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House Finance Committee on Health and Human Services
Interested Party, HB 33
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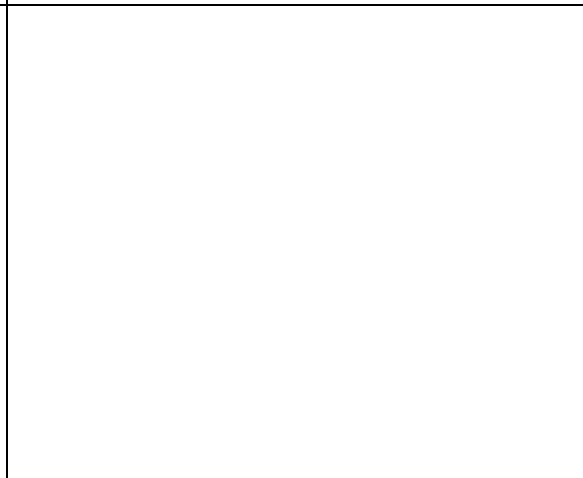
Chairperson Carruthers, Ranking Member Liston, and Members of the House Finance Subcommittee on Health and Human Services, Thank you for the opportunity to provide testimony on HB 33.

My name is Alicia Hopkins. I have a developmental disability and several rare diseases. I want to thank you for the opportunities to once again to testify about direct support and nursing wages. I had testified in the budget session in 2021. As you may recall I had included art in my testimony. That one piece lead to me painting 25 feet of art. My art is the stories of people across Ohio who have struggled to access home care. It is also how I survived my care crisis. Attached to my testimony, you'll see photos of art showcasing, the real stories of Ohioans impacted by the crisis.

Access to home care in Ohio is loaded with red tape. Every system that provides waivers- Ohio Department of Medicaid, Aging and Developmental Disabilities-has its own roll of red tape. I am what you will call a rare case as I was on a Medicaid waiver My Care Ohio before ever getting a waiver through the county board of Developmental Disabilities. #CareIsEssential to all Ohioans with disabilities and seniors. In Ohio having a waiver does not secure you access to care. It doesn't mean that you get the support you need. It looks good on paper to state agencies employing these waivers but it doesn't mean access is there.

The pay disparities among systems of care add to the problem. One in eight direct support workers are in poverty in our state. I have watched my providers over the years struggle because of low pay, systemic problems with payments of services rendered from state agencies and managed care plans and the lack of transparency to the mountains of red tape to just keep there provider number to administer care. Our state is an accessibility clusterfuck to both consumers and providers and there is no accountability with state agencies for consumers or providers around following the Federal Americans with Disabilities Act. Ohio must include a measure that brings oversight – a committee perhaps that assures Ohioans get the services and supports authorized and more so that everyone that needs care can access that care free of retaliation and discrimination.

In addition increase the wages we need parity across systems and oversight measures, There are other solutions that could help alleviate the impact of the crisis. Some of the solutions were implemented temporally during the COVID-19 pandemic through Appendix K..



i. **Temporarily modify provider qualifications.**

[Provide explanation of changes, list each service affected, list the provider type, and the changes in provider qualifications.]

K-2-d-i: The State permits the following:

- Allow waiver providers with an active Medicaid provider agreement to furnish waiver services across the delivery systems without being subject to additional provider standards and certification processes specific to the waiver programs.

All provider types which furnish the same or similar services between delivery systems are subject to the minimum Standards described below:

Ohio Department of Aging (ODA) -certified waiver providers meet the minimum standards to furnish the same or similar waiver services in the Ohio Department of Medicaid (ODM) operated waivers and the Ohio Department of Developmental Disabilities (DODD) operated waivers.

ODM-approved waiver providers meet the minimum standards to furnish the same or similar services in the ODA operated waivers and the DODD operated waivers.

DODD-certified waiver providers meet the minimum standards to furnish same or similar waiver services in the ODM operated waivers and the ODA operated waivers.

ii. **Temporarily modify provider types.**

If you are not familiar with Appendix K I am attaching with my testimony. It says that any provider that has a Medicaid number can provide care to people on waivers for Medicaid, DODD and aging in Ohio during the pandemic.

We hope that Ohio will keep the provision from Appendix K and train case managers in the future to have timely responses to federal pandemic emergency provisions, so people will have timely access to care as our system has been overwhelmed with red tape and access barriers. We must do all that it take to assure equal and fair access in anyway, we can. We are Ohioans who have been limited by the restrictive measures for far too long. No one should be forced to divorce a spouse to have them to be their provider or should a family be forced to live on their disabled family members income, because there is no ability to work outside the home and no workers to recruit to come in. It's time Ohio live up to its FAMILIES FIRST INITIATIVES.

However, I would like to remind you that solutions only work if They are in forced fairly and correctly. While, Appendix K in writing was a good policy, many managed-care plans ignore this approved federal document, blocking access to critical care. This includes homecare. Here we have a shortage of home care workers in there, and those that can provide care or not able to due to fraud by our managed-care organizations. I waited 17 months to contract an established medicaid provider under Buckeye Health Care in that time I could have gotten my 56 hours of authorized care I wasn't able to access my care as needed due to a lack of transparency and accountability. Meanwhile my managed care plan pocketed the higher rate of capitation payment the state pays for people on waiver services. Home care was not the only thing I couldn't access but that is whole other story. When I did find workers Buckeye Healthcare contracted providers they provided care and never received payment or they had there pay delayed 471 days as one of my providers did.

In a state of dismay and my thousands of emails to Ohio Medicaid and Buckeye Healthcare over 571 days I was given excuse after excuse yet Appendix K allowed me to use those providers. More so every

time I found someone to work with me the low pay, lack of cooperation from state agencies and McO plan and complicated enrollment process detoured me from access to care.

People with developmental disabilities have higher instances of being abused- you would never think that abuse would come from a healthcare organization's responsibilities for assuring the health, welfare, safety and care of people with disabilities yet I was bullied in my attempts to access care. The medicaid managed care system in Ohio lacks training for people with developmental disabilities and more so lacks trauma informed training for people with domestic violence situations.

I was on Over 200 days on back up plan on the My Care Ohio waiver in 2021-2022 due to red tape in our system around contracting, pay, recruitment of providers and abuse of power. It is my Olmstead Right to access Care... yet the rolls of red tape our system has allows for people to be abused, harmed and at risk for institutionalization. State agencies should be ashamed of themselves and how they have violated the rights of people with disabilities who need access to care.

In fact Medicaid should not be so inaccessible that it pushes you backwards into abuse and harm. Just for the record – We must invest in a home care workforce so that case management teams will stop telling people with disabilities to look for caregivers on Craigslist.

The low wages and inability to recruit workers for people on home and community based waivers through Ohio Medicaid, My Care Ohio, Ohio Department of Aging and Ohio Department of Developmental Disabilities has opened the door for people with to suffer mentally, physically and be subjected to abuse and harm.

Accountability goes along way and is about doing the right thing..... doing the right thing involves higher wages, clear pathways to provider recruitment and enrollment in all systems and transparency with provider pay for every state agency. When I advocate I don't see systems I see thousands of people who do not have access to care.

We should want to improve access to care- as we are number six in the nation with having the most elderly population. As people want to age in place and people with disabilities want to live and be active in there communities an investment in a living wage or the medium of at least \$20 an hour for home care workers is the most necessary and critical step for recruitment and retention of home care providers long term as the demand is growing rapidly. Every 4 seconds someone new needs a caregiver that's one or two heartbeats away from the sanctity of life.

Disability is only minority group you can join at any time in life. #CareIsEssential as costs go up let me remind all of you that the savings Ohio needs must come from your investment and commitment to community integration instead of your campaign investors who wrecklesly steer our state off track financially.

FYI It is very clear that it only 1/6 of the cost to provide care in the home where people can live, grow and thrive in their communities independently or with there families compared to the cost of institutional care. The pearls of the independent living movement are one investment that assures people better outcomes in life.

#NobodysDisposable but that is the message that Ohio Legislators will send if you do not invest in direct support worker wages and nurses on every system of care and hold state agencies, managed care organizations and case management agencies accountable to making sure people can access care without the red tape that exists.

Take 4 seconds put your hand over your chest can you feel your heart beating... as I mentioned disability is only community you can join at any time... We too, those of with disabilities, are human beings with a heartbeat and without your investment in provider wages more people will die as the system collapses... It's time to cut the red tape to critical and necessary home care by increasing wages for every system of home care in Ohio.

See Appendix K

<https://www.medicaid.gov/state-resource-center/downloads/oh-0446-0337-1035-0198-combined-appendix-k-appvl.pdf>