

Alicia Hopkins Budget Testimony
Ohio House Health Committee HB 96
March 5th, 2025

Honorable Chair Jean Schmidt, Vice Chair Kellie Deeter, Ranking Minority Member Anita Somani
Thank you for opportunity to testify on HB 96.

My name is Alicia Hopkins I have a developmental disability and I am also a self advocate. I want to share some things about Medicaid then I want to break the remainder of my testimony into sections as I have much to say around different state agencies budget proposals.

Growing up I watched my disabled mother be forced to deal with work requirements for Medicaid benefits. Back then the ADA was fairly a new law. My mother experienced hard core discrimination while trying access Medicaid benefits. The work requirements either forced her to work at a job site without accommodations or to in debt herself in the education system. My mother saw both sides of it and reality didn't equal long term employment.

My mother was always resourceful that I thank her for. My mother worked a collection of seasonal and sub-minimum wage jobs for over twenty five years. Living in rural community where jobs were limited for many then the reality of no drivers license it divided her from other applicants applying for similar jobs.

As you write the work requirements for Medicaid I urge you to take into consideration people who don't have a drivers license to drive and banning employers from discrimination around having a requirement to have a drivers license for non driving positions . More so lack of transportation is transparent and a challenge in our rural communities for those searching for employment. These are all factors must be considered in establishing work requirements for people on Medicaid.

None the less I also think that those who do volunteer service work, caring for family member of Veteran, Senior Citizen or disabled family member should be exempt from Medicaid work requirements.

Work Requirements are not new however this is a repeated issue in every state budget. The Medicaid Director wants to help people reach their full potential but this reality of work requirements makes me question why there are so many underutilized job centers, work programs that Ohio's own citizens know nothing about and why the state won't invest in putting people to work in an almost deserted care economy that makes up a huge portion of our budget. Seems to me like people are holding the line in one area in order to keep people from access to healthcare or even paid employment in another arena.

To add to this is as a state the more we push work requirements for people on Medicaid; Ohio needs to also consider why there is under utilization of job programs for Ohioans. Why are Re-Entry Programs under utilized for putting people with criminal backgrounds back to work. Overall why are job programs and job centers underutilized. It seems as though the qualified to work are detoured by red tape in its own system; we must cut the red tape to employment and build on that.

I understand that cuts are happening from the Federal Level in terms of the Expansion of Medicaid. No one is happy about cuts in budget. This pro-employment state must also chose to use money that exists for employment in a way that can actually help people go back to work. It seems as

though we need to look at employment from lot of different angles. In this sense before anyone cuts are made by any one from Medicaid maybe do a study of employment in Ohio and the barriers to employment then work with resources our state has to help people get back to work to be more independent and stable.

Over all... We ask Governor Dewine and Ohio Legislators to not make any drastic cuts to Medicaid that would affect people with disabilities, aging baby boomers, or elderly.

Medicaid Budget

I would like to thank the Ohio legislators for budget increases for home care workers and direct support professionals two years ago.

The impact of the wages really helped many direct support professionals, Nurses and and home care workers.

I want to share just a few stories around this. Before the wage increases home care agencies were working some caregivers 24-72 hours on wake cases for people with developmental disabilities. This caused caregiver burn out and opened the door for abuse and neglect. Since the wage increases agencies have some additional leeway with hiring people to care for people with disabilities and older adults.

It isn't an overall fix and I have many ideas think that legislators need to hear. I believe we need to be resourceful and utilize other services available statewide to build an overall recruitment plan which will be detailed below in (Appendix A) of my testimony.

I have seen the statewide impact as one direct support professional who use to walk 4-5 miles a day to and from work can now afford the ability to make car payments and take on more shifts as the raises made so she doesn't have to walk to work.

I saw on social media that one dsp was able to use extra money to invest in a kitchen sink with real facet. These little things make a huge difference.

The biggest challenge I still see is the ability to work and get paid timely. If people cannot get paid timely they will leave the field which is already in DIER care crisis. The states OMES system for payment that Medicaid touts about still has many workers including our home care nurses and direct support professionals in crisis over the frequent billing problems. If you visit the [Ohio Independent Providers facebook group](#) you will find many people in crisis over pay problems associated with OMES and the Electronic Visit Verification issues.

We ask the Legislators to cross examine the medicaid director on just how many providers have existing billing problems and what actions will do to actually improve this system.

In the last state budget Ohio chose to approve the expansion of My Care Ohio without truly understanding the impact it has had on Ohioans who were apart of the demonstration. This idea of #NothingAboutUsWithoutUs is true that you expanded a service that has negatively impacted many Ohioans without even asking how it's impacted us. I disagree with the premise of further expansion of My Care Ohio.

Healthcare is political it isn't just about saving money in your state budget. I published a book Audacity2speak in 2024 it details my 8 years of horrific experience on the My Care Ohio waiver

program. A lot of programs in Ohio are very complicated for people but to add insult an expansion calling it Reimagined Medicaid is surely a Public Relations Scam wasting tax payer dollars. To Reimagine something like My Care Ohio truly would mean hearing from people who have lived this ten years of nightmares.

The events existed around Ohio for the public didn't actually reach many of people served by the demonstration.

People want to see real change to systemic problems that run rampant in the My Care Ohio Program. I have never seen Ohio do anything that truly provides public stakeholders input to those who actually use the programs

It bothers me that the disabled and elderly voices in Ohio have gone unheard about My Care Ohio. The program itself offers no coordination of care. People with developmental disabilities forced into My Care Ohio those folks were disabled before 22 have nursing needs but are Dual Eligible for Medicare and Medicaid the population of folks some who have rare diseases and every day are fighting battles the Legislators know nothing about but should...

My Care Ohio Systemic Problems made it so my friend died from lack of access to heart transplant for a hospital mco plan wouldn't contract with.

My Care Ohio Systemic Problems made it so a women from cleveland with rare disease couldn't get life saving medication and had worse side effects and ended up with serious medical scare.

My Care Ohios Systemic Problems made it so a women with a traumatic brain injury from Akron couldn't get proper mental Health and substance abuse treatment so the women committed suicide.

My Care Ohios Systemic Problems made it so providers won't take certain plans because payment for home care services made some providers homeless over non payment from managed care organizations plans

My Care Ohio's Systemic Problems made it so a man had a ceiling track in his home and hoyer lift broken but unable to be repaired and guy became bed bound got bed sores and had to temporarily go into facility and had to change managed care plans and still can't get any assistance to fix his hoyer or ceiling lift.

My Care Ohio blocked transportation access for a women to see a specialist in Toledo for her Rare Disease.

My Care Ohio caused a women with profound developmental disabilities to end up in a situation around human trafficking and abuse.

I can tell you story after story of people around Ohio who have suffered immensely from the struggles of My Care Ohio. To expand a system so broken that people are dying or being institutionalized from the effects of it what are you thinking? How do you hear from people and families are affected by My Care Ohio?

Before Ohio runs another Public Relations Scam why not create a committee to investigate the abuse and systemic issues that exist within My Care Ohio Program. I urge the Legislators to create a committee to investigate the abuse of people served on My Care Ohio program ... it seems as though you have that authority and any hearing you hold people will speak up. My Care Ohio is not reimagined it's same shit show of 2014-2024 nothing reimagined about it.

While my testimony may seem harsh it's wise to #Listen2DisabledPeople and hear our stories we have many stories.

I mentioned I have a developmental disability. Under the My Care Ohio program I had zero support for my developmental disabilities. It did not exist and it legit took moving to a waiver under the County Board of DD to get the right supports in place that wasn't easy. I had to go thru hell to get my needs met and no Ohioan should go thru what I have been through.

Many people on My Care Ohio need access to mental health care this program has made that impossible just something to think about. Many mental health providers don't want to accept My Care Ohio due to low ball or non payment for services from mco plans.

Expanding Behavioral Health Access is truly important to Ohioans across the state. The Algorithm of Care is problematic to access care. The managed care plans often low ball pay to providers, there are delays and even directories don't have accurate information. This idea of access to mental health or behavioral healthcare is almost non existent. Specialized Behavioral Health just doesn't exist in Ohio,

People with Complex Disabilities are being left behind in the system of access to care. Inpatient mental health services do not exist for people who need crisis intervention or support who have dual diagnosis of mental health and intellectual and developmental disabilities.

I serve as a member and Advocate for Link Center National Steering Committee for Mental Health and Intellectual and Developmental Disabilities in my work on this Committee I had heard lot of stories of access to care from a national perspective we are involved in lot of advocacy around making 988 more accessible. I am grateful Ohio medicaid wants to work on this as well.

In Ohio it is one thing to make something accessible and another to actually have referrals that are accessible. In saying this mental health care for people with complex disabilities does not exist in Ohio.

A good friend of mine who has epilepsy and a rare disease needed mental health services inpatient due to Psychosis. There was only one facility in the state that would take him. That facility denied him access to critical epilepsy medication for 48 hours while they got his medications through the approval process. It should never take 48 hours to approve a life saving preventive medication for anyone that without that medication they can die. His family even offered their own supply but facility policies prevented him from receiving this medication. To make long story short this man's need for mental health inpatient care turned to him being on a ventilator fighting for his life.

Ohio wants to expand access to mental health or behavioral health services please don't forget the #NothingAboutUsWithoutUs concept again here because #NobodyIsDisposable and if we don't truly look at services that are needed but don't exist then any expansion you offer will leave behind people who have needed help but there is no where to turn.

In an essence the goals to expand care for youth with complex behavioral needs you will miss mark because many of those youth also have complex medical needs too.

I also urge the State to consider policies for all behavioral centers that assure that people are treated with dignity and respect. There are many issues popping up in the news around facilities using improper restraint and other abuses happening to people with disabilities.

I fully support the budget goals around the Medicaid Buy In Workers with Disabilities Medicaid.

Dodd Budget

Supported Decision Making has been life changing for me. I have my autonomy of life and I am my own guardian today because of the support I receive from my Supported Decision Making Team.

Supported Decision Making has helped me learn real life skills, learn to problem solve, work through conflict and make informed decisions about my life in many areas.

I believe that we fully need supported decision making in Ohio across all waiver systems not just the dodd systems. The reason I say this is because there are many people with developmental disabilities served by the Ohio Department of Medicaid and Ohio Department of Aging.

I also believe that we need to be accessible and inclusive and not over legalize this amazing concept of support. The fear as a disabled advocate is that we will over legalize it and make it inaccessible.

A blind person friend of mine pointed out that she can't sign a document in person with a notary she would be excluded from utilizing supported decision making even though this is something could benefit her. I saw in context of the rules being written that public notary was a requirement this requirement excludes people who can't sign their own name, blind communities and potentially other who aren't able or sign or even afford the cost of notary. I also think that options for digital signature with two witnesses is potential fix and should be allowed in the context of a technology first state.

More so everything needs rules i get it but we have to consider how the frame work of rules are established. Example the alteration of document amendments happening or a person simply choosing to ask for help in an area of life they never asked for help in - do we legalize it so much that this is contract these people can only help with xyz and nothing new can be asked or considered without an amendment or change to contract? Are we truly making this about person centered options or are we trying to over legalize it without proper solutions.

I firmly support Supported Decision Making from All sides but the language in the budget needs serious revision to include aspects of accessibility in supported decision making contracts. The Ohio Department of Developmental Disabilities Services should learn from people utilizing Supported Decision Making to form rules around it. I agree with parts about being free from liability. I fear that so much control over something that is a great support may detour people from pursuing it. I ask that legislators consider changing the language around requirements of public notary and also allow for digital signature, use of signature stamp and other means for signatures including two witnesses without notary requirements.

In the Developmental Disabilities Budget there is also an add on rate for patients with Ventilator Care. I understand this is solely for dd patients served under county boards of developmental disabilities. We also have ventilator patients with developmental disabilities served on Medicaid and Aging waivers who need care and are unable to recruit nurses because of low pay so I ask that Medicaid Director and Medicaid Budget include a similar add on and both systems legislators grant this add in for care.

In regard to rules for out of state travel for people with developmental disabilities. I ask that out of state travel of vacation verses medical travel be clarified in rules.

Under Health Related Activities in budget bill.

I would like Ohio Department of Developmental Disabilities to provide clarification on the rule being considered for revision around the epinephrine training if the Epi pen Training from an RN nurse will still be required since the requirements to remove the medication administration training for epinephrine injectors. I do believe some level of training still needs to exist for people who are administering this medication because it is a life or death situation for some people.

I have a rare disease called Mast Cell Activation Syndrome. I require assistance to administer Epinephrine this is life or death for me and without some type of training for the epi pen it creates obstacles could delay emergency life saving medication.

I also ask that state allow medication Octreotide for use of post prandial hypotension or orthostatic hypotension around digestion to be administered intramuscular or subcutaneous under this rule as well (See Appendix B Dr Grubb Toledo doctor who uses Octreotide for treatment of Orthostatic Hypotension) this would eliminate the need for a nurse and allow for direct support professional to administer it. While Orthostatic Hypotension is Metabolic Disorder related it isn't directly classified as one.

Family member Authority to Administer Medication

I agree with allowing families to administer medication without nursing delegation or medication certification. I also ask that rule provide clarification if this is only for unpaid or does it allow paid family caregivers in same context to be exempt from the certifications and training.

I ask the state not to remove developmental disabilities trust that helps people get out of institutions and back into the community this is viable resource and should be continued.

Opportunities for Ohioans with Disabilities Budget Proposals

I ask that continued funding be approved for Brain Injury Education Programs as 1 in 4 Ohioans have some type of brain injury. These programs help people on many systems of care.

I also ask you consider money for programs for the blind to learn how to use white cane and employment supports.

Thank you to letting me testify for HB 96 and also ask see attached Appendix A and B in bottom this document .

Alicia Hopkins

Appendix A Recruitment Plan for Direct Support and Home Care Workers

Ohio is a Pro - Jobs state. Even the Medicaid Director stated that she wants people to reach full potential and find their abilities. In being a Pro- Jobs state wanting people to go back to work we need to address the crisis with the shortage of workers in Direct Support Professionals and Home Care and the systemic barriers to why people cannot access providers or care.

I propose that Legislators provide an allocation of funds to Department of Medicaid, Aging and Developmental Disabilities specifically to be used to recruit direct support workers on all systems of home care Ohio Dept of Developmental Disabilities, Ohio Department of Medicaid and Ohio Department of Aging in a way that includes partnerships with Ohio Job Centers, Ohio Department of Job and Family Services, Ohio Attorney General Office and organizations like the American Red Cross who offer First Aid and CPR Certification.

Ohio job centers were meant to be one stop shops. Every year this state gets Workforce Investment Act dollars that don't get fully used. We are a Pro-Jobs state, we see a critical area that needs to employ people and we must act on this idea of recruitment of workers.

Stop wasting money towards phone applications that don't work. Invest in a home care workforce through partnerships with existing agencies and resources available.

Utilize Job Centers as a place to recruit home care workers. Background checks at discounted prices or partnerships formed with the Ohio Attorney General's office and Bureau of Motor Vehicles, a job center being exactly what it meant to be a place to learn first aid and CPR, acquire state tested nurses aide training, job fairs for home care agencies/representatives from state agencies on the ground working to help people apply to become independent providers.

We are a state of many resources we don't connect dots often and need to. Hold county and regional hiring fairs at local job centers over 3 days you can get these critical trainings and apply for much needed jobs. Ohio wants people to go back to work but the delays are on the state too as many families can't even leave their homes because loved ones can't recruit home care or direct support workers.

We need Ohio to invest in healthcare jobs for people who utilize our Medicaid budget to live independently.

We need legislators to see this critical need and create a task force or budget allotment for Medicaid to build a recruitment plan that is carried out that involves a true path to bring Ohioans to help other Ohioans thru the economy of care.

When I say the care crisis is bad it truly is. The wages did help some of our challenges. The wages alone do not fix that fact - we just don't have the number of people who can serve our disabled and aging population and in order to get that state must invest in a recruitment plan being built in to medicaid, aging and dodd budgets to further expand our home care workforce for people with developmental disabilities, people with physical disabilities, the aging and those who need long term care.

Outline of Recruitment Plan

1. State agencies work with local ohio department of job family services and county Job Centers to create events for sole purpose of recruitment of direct support and home care workers.
2. Partnerships formed with Ohio Attorney General Office to help discount or provide background checks to low income Ohioans in need of employment who are applying to direct support, nursing or home care jobs.
3. Partnerships with the American Red Cross and Ohio Department of Health and STNA training programs to provide First Aid/CPR training and STNA training to anyone attends these hiring events at discounted or free or charge with agreement people will work at least one year in home care.
4. Partnerships with county job centers, state agencies and home care agencies, agencies provide direct support care to people with developmental disabilities and aging to hire people for direct support and home care jobs.n
5. State Agencies partner with Ohioans to create further expansion of home care and direct support jobs with application for independent provider jobs.

Outcome: A recruitment plan for each county job center to be utilized would bring more jobs to Ohio economy, increase direct support workforce and help people live independently in their homes. It would get people back to work and build more independent Ohio.

Appendix B is link to Research Study by Toledo, Ohio Cardiologist Dr. Blair Grubb on the use of Octreotide <https://pubmed.ncbi.nlm.nih.gov/20535001/>