

Alicia Hopkins
 Chairperson Romanchuk Vice Chair Steve Wilson
 Ranking Member Ingram thank you for the opportunity to testify on HB 33.
 Interested Party HB 33 May 11th 2023

My name is Alicia Hopkins. I am the Chair of Ohio Nursing Crisis Advocacy Committee and involved in several other advocacy groups. I have a developmental disability and a rare disease and I am on an I/O waiver through a county board of dd.

Today is May 11th 2023. It is also a historical day as it was the day that Lois Curtis a disability advocate took her case L.C. v. Olmstead to the Courts. Her court case became a monumental hallmark of the independent living movement and the right to access community state funded supports for independent living.

Ultimately independent living and home and community-based services and supports saves lives and millions of dollars every day. In Ohio we have many different types of home and community-based waivers. It's imperative that legislators understand the differences and systems and how the state budget plays a role in funding each critical provider type through each state agency.

Ohio Department of Medicaid	Ohio Department of Aging	Ohio Department of Developmental Disabilities
My Care Ohio PCA Program Ohio Rise Ohio Home Care Waiver Ohio Assisted Living Waiver SRS Waiver PDN Nursing	Passport Choices Home Care Attendant Program PACE Self Directed My Care Ohio	Individual Options Waiver Self Waiver Level One Options

The Governor proposed wage increases for direct support workers in only the DODD system but we need raises all across the board and parity among systems of care. We need these critical investments in home and community-based services and supports to assure equal and fair access to care for every system of care through Ohio Medicaid, Ohio Department of Aging and Ohio Department of Developmental Disabilities.

In addition to an aide level of care we have folks who need Nurses and a 19% raise in the Medicaid budget for Home Care Nurses is not enough. This would make it so our RN will make around \$38 an hour as an independent provider. This is still very low and less than surrounding states. In Ohio this rate for RN would be less than the Kentucky LPN Rates.

Below is our table taken from the Ohio Nursing Crisis Advocacy Committee Sign on letter that was submitted during House part of the budget on April 18th, 2023 (See footnote of testimony for additional documents)

Medicaid Nursing & LPN Rate Per Hour Comparison of Surrounding States

Provider Type:	IP RN	AgencyRN	IP LPN	AgencyLPN
Ohio Current ₁	\$29.84	\$37.00	\$24.96	\$31.28
Ohio Requested₂	\$46.00	\$52.00	\$38.52	\$46.00
Michigan ₃	\$52.72	\$57.84	\$44.84	\$49.16
Pennsylvania ₄	X	\$66.20	X	\$44.08
Indiana ₅	X	\$47.96	X	\$47.96
West Virginia ₆	X	\$44.08	X	\$44.08
North Carolina ₇	\$45.00	\$45.00	\$45.00	\$45.00
Kentucky ₈	\$39.60	\$39.60	\$39.60	\$39.60

Table Notes:

Note: Our table is based on the unit rates, not the base rates, since the majority of hours worked are reimbursed at the unit rate. We converted the unit rates into the hourly rates, for ease of understanding.

Sources: The sources for the above table, and the table notes below, are listed at the end of this letter. The source number corresponds to the subscripts.

X – Indicates that the Private Duty Nursing Independent Provider rates are unavailable for these states

WV - Had a temporary rate for all providers of \$74.92/hr during the pandemic from July of 2021 to March of 2022⁹; Current rate is \$11.02/15 mins or \$44.08/hr per Mr. Hill from West Virginia Medicaid⁶

NC – Had multiple temporary rates during the pandemic; These rates varied from \$41.60 to \$47.84 per hour for Independent RNs & LPNs and \$31.20 to \$45 per hour for Agency (Congregate) RNs & LPNs⁷; The table above includes only their current rates⁷

KY – Had a bill that approved a 10% rate increase to go into effect in the 2022-2023 fiscal year¹⁰; This increase was added to their 2019 rate found in the KAR⁸ (36x1.1=39.60); The bill also included an additional 10% rate increase to go into effect during the 2023-2024 fiscal year, which begins on July 1, 2023; It is NOT included in the table because it has not yet gone into effect¹⁰

Ohio pays less than surrounding states for nursing care as you can see from the chart above. This was taken from the Ohio Nursing Crisis Advocacy Committee Testimonies submitted to Ohio House on April 18th, 2023. In addition, low wages, we are finding that there are no incentives for people to join our community of caregiving for those receiving Medicaid Nursing. Those affected are children, adults and older adults with complex medical needs. They have waivers through Ohio Department of Aging, Ohio Department of Medicaid and Ohio Department of Developmental Disabilities. It happens to be that Medicaid still pays for Nursing Care when people are on the other waivers too . Just for the record the

DD crisis affects all waiver types and more so there are people with many disabilities that need this crucial access to care.

Did you know that the cost of ICU bed with machines in a hospital is about 40,000 a day to an Ohioan who needs an ICU level of care? The cost of RN Nurses at home is roughly \$700 dollars a day. People who need this level of care have an Olmstead right to receive that care at home. It is impossible to recruit nurses at \$28.84 an hour... this is the amount after the first hour of pay. Our Nurses wages drop \$10 after the first hour yet their care needs are no different from the first hour to the fifth hour and so on. We need to assure that every hour of pay is the same and our Nurses do not drop down \$10 dollars an hour after the first hour. Eliminate the base rate and pay the same rate every hour.

Some agencies and independent providers are still battling pay problems. Due to Medicaid rates being so low some Nurses work by the case instead of by the hour.

\$32 a visit was what one Agency Nurse shared with me recently and how they don't get paid by hour paid by the visit. If that visit is four hours they are getting less than minimum wage per hour.

Without Nurses people who need ventilator care, tracheostomy care, G Tube Feeds and IV care are left in the dark... If we shine light on the overall Ohio Direct Support Crisis, we will find that Medicaid Nursing hasn't had much discussion but needs more. Our nurses save our state money, but they give people opportunity as every Ohioan should have. Home Care Nurses help families thrive, help people with disabilities be active in their communities and offer pathways to independence.

As a person with a developmental disability and a rare disease patient, I struggled under the My Care Ohio waiver system before ever receiving a DODD waiver. I could not access, critical, life-saving care due deceptive practices of managed care organizations like buckeye healthcare, they made it made impossible to access the care I needed that is why an oversight committee has always been needed, and always will be needed because people like myself have experienced garbage care from the state's managed care entities with no end in sight until a person is in a vulnerable dangerous situation like I was.

Things got so bad in my situation that Buckeye healthcare never paid my nurse or my personal care aides. My doctors were worried for my safety because I could not access nursing care. Buckeye healthcare had the nerve to go to my doctor, and ask him why I could not suction or administer a breathing treatment on myself, while I was having anaphylaxis, just so they could save from paying

for nurse for me. Chair Romanchuk or any member of the Medicaid Committee If you were having an allergic reaction where your airway is obstructed, would you be able to administer your own medication and perform an ER level of care On your own for yourself? That is what buckeye healthcare expected me to do to myself, was to give myself breathing treatments and do suctioning on My own. Last I checked I only have two hands. When I asked for a nurse to also help me be medication compliant and to alleviate my symptoms of my rare disease Buckeye still refused, I got one after four months they never paid her so she quit. I had to go to ER and infusion centers for port access and emergency meds could be done in the home..

My life was unstable, and the only thing to do was relocate, because buckeye healthcare was going to kill me.

It took me almost 5 months to obtain an emergency waiver through county board of dodd. I was truly in an emergency but that's whole other story.

Georgie and I are both rare disease patients, have developmental disabilities and are people who are medically complex who want to speak up about the need for nurses and nursing care at home.

We both have a rare diseases Ehlers Danilo's Syndrome and. Mast Cell Activation Syndrome. Both of us are

very young well under 40. We both have a home and community-based waiver but on different systems however our access to nursing care is limited because of the low wages and systemic hurdles that make it so care is more difficult to access.

I mentioned I was on My Care Ohio, now I am on a dodd waiver. I can access some sort of nursing care now however not everything can be done at home and still rocky places in my stability of my care needs. I still have to go to ER or an infusion center for port access and IV fluids. I get one hour of actual nursing a week provided by the Nurse of this panel.

For those on a dodd waivers like myself direct support workers can earn a medication certification and do some nursing tasks. As a rare disease patient it's trial and error on a daily basis.

For those on ODA, ODM and My Care Ohio the process to become a home care attendant is a living nightmare that I actually lived but Georgie lives every day. The reality is that some people are not even able to use HCA or DSP with medication administration training. It's difficult to recruit Nurses when Direct Support Workers (otherwise known as aides non medical aides) with add ons

make more than our LPN Nurses. By Ohio ignoring this nursing crisis you are a part of the problem.

This overall care crisis – The Ohio Direct Support Crisis affects 130,000 Ohioans with disabilities both children and adults, older adults and people served by multiple state agencies.

This Ohio Direct Support Crisis with direct support workers and home care nursing crisis was an issue before the pandemic. I went and sat down with Senator Vernon Sykes in December 2019 in Akron, Ohio with a 26 page list of families just on facebook alone who needed care... it's 2023 if I made that list again it would probably be a couple hundred pages. People are desperate for access care.

There are thousands of adults and children with disabilities unable to access Nursing Care at home... yet people needing ICU level of Care have the right to receive care at home where it is the safest, most cost effective, offers the opportunity to live life with every opportunity possible. Four years later Legislators are still in the pockets of your lobbyists and campaign donors forgetting about Ohios most vulnerable population... children with disabilities you have abandoned... adults with disabilities and older adults with disabilities have been left in the dark.

Nobody is Disposable yet that is the message your committees put off when you leave critical funding off the table for Medicaid Nursing Providers who need critical care. We are not disposable we are Ohioans too...

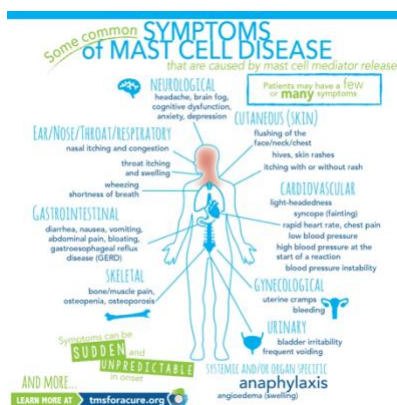
We need legislators to bring an oversight committee to assure people with disabilities and older adults get the care authorized. We also need to make sure managed care plans are timely in contracting established Medicaid Providers. In a meeting this year with Jesse Wyatt an employee from Ohio Medicaid we learned that managed care plans are allowed to discriminate about who they will accept and who they don't as a Medicaid provider for home care. These discriminatory practices must stop. I firmly believe that I why I waited four months for a nurse and 17 months for a personal care aide, when I was on Buckeye to access care. Without an oversight committee for states agencies like Ohio Medicaid you contribute to abuse and harm of people with disabilities that can be sharply prevented with oversight.

More so all systems that provide payment for care must pay providers timely. This is the number one reason right now why our long time Nurses are walking out the door. Medicaid has delayed payments/reimbursements for months now. This is not the first time this has happened. Some providers have never received

payment from their clients plan and had to quit-that's what happened to a nurse I had in 2021. These payment problems existed in 2013, 2016, 2017, 2020 and again here in 2023. Some of it is managed care but a lot of It is a lack of responsibility from state agencies like Ohio Department of Medicaid, Ohio Department of Aging and Ohio Department of Developmental Disabilities. These pay problems run deep and affect multiple provider types.

As a Rare Disease patient, I struggle to get my needs met. I have a mast cell protocol written for nurses but tragically adapted for direct support workers. Mast cell activation syndrome is a disease that affects multiple systems of the body. At any time I can go into Anaphylaxis and have a variety of symptoms ranging from choking. To hives, to tachycardia to passing out, to airway restriction. In 2020 I had over 75 episodes of anaphylaxis and 2021 I had 62 episodes and 2022 I had 45 and this year had quite a few episodes.

I have included an infographic about Mast Cell Activation Syndrome for your reading from <https://tmsforacure.org/printable-resources-infographics/>



At one point during Ohio House of Representatives Hearings someone suggested Group homes for disabled people and I want to say group homes are not an answer for people who are medically complex. Nursing Homes are not acceptable places neither for people like myself or others who are Medically Complex. Anywhere where two or more people must receive care from one provider is unacceptable and violates the right to federal free choice in provider and more so creates an institutional injustice for people who want to live, thrive and be active in their communities.

The average nursing home patient gets 14 minutes a day of care. In a staffing crisis people on ventilators, people who need suctioning, Gtube care, port access

and other services of these such take more than 14 minutes alone plus people with disabilities have the right to this care at home it is an Olmstead Right.

Ohio has left the medically complex in the dark without an ability to receive services authorized instead they offered deceptive practices that lead to a lack of care, lack of caregivers, and red tape in our system.

In addition, any measures in the budget bill related to provider overpayments should be hexed immediately given the circumstances around payment/repayment of services rendered and the extreme delays set forth by state agencies like Ohio Department of Medicaid, Managed Care Entities and Public Partnerships. Our providers have suffered enough with new rules and no ability to have input while legislators have allowed ODM to roll out a system with inconsistencies, deep flaws and payment issues that have caused unpaid bills, drops in credit scores, vehicles repossessed and other hardships.

Pay problems = Red Tape to Access care on every system of care.

That red tape makes is so no one can access care. We should be ashamed of ourselves for letting a care crisis get so bad that people have been abused, harmed and even died from staffing shortages this bad. Nobody is disposable not one single Ohioan yet without an investment in all systems of home care and all provider types we will create an injustices that can be prevented. Thank you for your time and if you have any questions, my email is audacity2speak@aol.com

I want to end my testimony by sharing names of people who need this critical access to care and the number of hours they have authorized of care but aren't able to obtain that care. We need oversight for every system of care and pay raises too... we need you take your hands of pockets of your lobbyists and help people with disabilities both children and adults and older adults who need critical access to nursing and home and community based supports.

Corey from Greene County, Ohio needs 30 hours of Nursing a week.

Noah from Cuyahoga County, Ohio needs 112 hours of Nursing a week.

Kelley from Preble County, Ohio needs 42 hours of Nursing a week.

Jerry from Perry County, Ohio needs 40 hours a week of Nursing.

Liam from Warren County, Ohio needs 56 hours of Nursing a week.

Danielle from Coshocton County, Ohio needs 85 hours of nursing a week.

Kendra a 17 year old from Montgomery County Needs 73 hours of nursing a week.

Ronda from Perry County needs 40 hrs of nursing a week.
Declan from Cuyahoga County, Ohio needs 50 hours of Nursing a week.
Domenic from Medina County, Ohio needs 56 hours of Nursing a week.
Jaime needs 112 hours of nursing a week
Triston needs 70 hours of nursing a week.
Rick from Lake County, Ohio Needs 112 hours of nursing a week.
Aryia from Lorain County, Ohio needs 80 hours of Nursing a week.
Rachel needs 60 hours of nursing a week.
Margarita from Lucas County, Ohio needs 20 hours a week of care.
Ezra needs 24 hours a day 7 days a week of nursing care.
Devan needs 112 hours of nursing care.
Kerry from Tuscarwarus County, Ohio needs 4 hours of nursing and 56 hours of aide care a week under her Medicaid waiver.

Jessica needs 42 hours of Aide Care a week under her Medicaid waiver.
Meaghan, 20 hours per week, Greene county, DSP
Natasha from Warren County, Ohio needs 24 hours a week of care.
Diane from Summit County needs 14 hours of DSP Care a week.
Christia from Medina County, Ohio needs 25 hours of DSP Care a week.

Footnote

https://search-prod.lis.state.oh.us/cm_pub_api/api/unwrap/general_assembly_135/chamber/135th_ga/ready_for_publication/committee_docs/cmte_h_finance_1/submissions/cmte_h_finance_1_2023-04-19-0900_369/nursingcrisesletter.pdf

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