Georgie Elson
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Thank you for the opportunity to testify today Chairperson Dolan, Vice Chair Cirino, Ranking Member Sykes, and Members of the Senate Finance Committee. My name is Georgie Elson, I am a Disability Advocate, a Medicaid Home and Community Based Services waiver recipient through the MyCare Ohio Program, and the Co-Chair of The Ohio Nursing Crisis Advocacy Committee. I have multiple disabilities including Autism, TBI, Ehlers Danlos Syndrome, and many of its related comorbidities. May is EDS awareness month. I use a reclining power chair; am limited in how long I can sit upright; experience countless daily subluxations & dislocations; and receive daily IV fluids & medications through a central line, for which I depend on nursing services for. I rely on IV fluids to manage my POTS, Gastroparesis, and Mast Cell Activation Syndrome. I experience anaphylaxis daily requiring me to depend heavily on IV Benadryl to stay alive.

The legislature has been hearing a lot about the need to increase direct care wages to $20 an hour from past testimony, like the testimony I previously gave to the House Finance Subcommittee on Health and Human Services, and from other methods of contact. That is an essential action that needs to occur for several reasons. However, there is another big aspect to this Care Crisis that's often left out of conversation: The Ohio HCBS Nursing Crisis. Due to the lack of attention to this serious issue, that will be the part of the crisis I will primarily focus my testimony upon today. While the current proposed rate increases for direct support aides is a step in the right direction, it is important to know that the proposed increases to $17/hr in 2024 and $18/hr in 2025, are both inadequate, and that HCBS nursing providers are separate and not included in this 36% increase. The situation is just as, if not much more dire, for waiver nursing, and yet it has been left largely unaddressed. While a proposed increase of 19.9% has been included, it is still completely inadequate.

Our group, The Ohio Nursing Crisis Advocacy Committee, created a social media awareness campaign to discuss the Nursing Crisis last month. We answered daily questions on the crisis, held live streams, created graphics, interviewed others impacted by the Nursing Crisis, and we tagged A LOT of legislators. It is my hope that you saw our posts and learned about the impact this crisis is having on medically complex ohioans, Ohio nurses, and Ohio families.

It is true that it is very difficult to find personal care aides in Ohio, but it is even harder to find waiver nursing providers. Nurses have more work opportunities with their training and experience. They can make significantly more in other jobs that may be easier and usually come with actual benefits. Ohio pays Independent RN nurses $29.84/hr and Independent LPNs $24.96, after the first hour (1), while the average pay for an RN outside of the waiver system is $40.17/hr(2) and the average for LPNs is $31.02/hr(3), in the rest of Ohio. Those average rates increase substantially with more years of

experience. Even more importantly, every single state that surrounds ours, pays SIGNIFICANTLY more to Medicaid Waiver Nurses than Ohio does. On the lowest end, Kentucky pays Independent Nurses, both RNs and LPNs, $39.60/hr - which is about $10-15 more per hour than what Ohio pays. On the higher end, Michigan pays, $52.72/hr to their Independent RNs, which is nearly $23/hr higher than Ohio pays them, and Pennsylvania pays $66.20/hr to agency RNs, which is $29 more per hour than Ohio pays. (PA doesn't have independent providers.) Please see the included chart below of this vital information with sources listed at the end of this document.

Medicaid Nursing & LPN Rate Per Hour Comparison of Surrounding States

Provider Type:	*IP RN*	*Agency RN*	*IP LPN*	*Agency LPN*
Ohio Current[1]	$29.84	$37.00	$24.96	$31.28
Proposed 19.9%	$35.78	$44.36	$29.94	$37.50
Ohio Requested[2]	$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 2022[9]; Current rate is $11.02/15 mins or $44.08/hr per Mr. Hill from West Virginia Medicaid[6]

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 & LPNs[7]; The table above includes only their current rates[7]

KY – Had a bill that approved a 10% rate increase to go into effect in the 2022-2023 fiscal year[10]; This increase was added to their 2019 rate found in the KAR[8] (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 effect[10]

The low wage is, by far, the biggest reason for Ohio's HCBS Nursing Crisis and the reason so many of us cannot staff the essential nursing care we have been authorized for. At the current rates, Ohio is sending a clear message that our state does not value these nursing providers, the essential work they do daily to keep individuals alive and out of the hospital, nor the individual consumers authorized for these services who cannot access this live-saving care, and as such, are at a very high risk of being institutionalized.

Legislators and the public really need to realize that due to many of our complex health needs, and our need for constant one-on-one care, many of us medically complex individuals could not actually survive institutionalization. For many with very complex needs, institutionalization is a death sentence. With such low staff to patient ratios, that have only worsened since the pandemic, many would not get the essential life-sustaining care they require in these settings, which seems to be severely overlooked when these conversations come up. One legislator previously suggested more group homes and remote supports as the solution to this state manufactured provider crisis, caused by a lack of a living and competitive wage. First of all, remote supports are completely useless when what you need, is nursing care to provide IV medications, suctioning so you can breathe, or feeds to be set up through a feeding tube. Furthermore, what is being misunderstood is that some clients truly need eyes-on 24/7 care. In fact, some need two-on-one care because they require 24/7 nursing and aide services, both. That is not something that can happen in a group home with multiple clients and one provider. Additionally, group homes, hospitals, and institutions alike are short on staff too, so shifting people around when there is inadequate care and staffing crises, due to low wages, across the entire system, solves absolutely nothing.

The other thing I would like to remind everyone of, who's listening today, is that we are human beings with rights. In the Olmstead Decision, the U.S. Supreme Court held that we have the right to receive state-funded supports and services in our communities. Forced institutionalization is segregation and discrimination. The ADA states that services provided to people with disabilities must be provided in the most integrated setting as possible appropriate to their needs (4). The most integrated setting is one that "enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible" (4). The Olmstead Lawsuit was actually first filed in the state of Georgia exactly 28 years ago today – May 11, 1995. That happens to also be the year I was born, and yet the Olmstead Decision has not been fully realized. Institutional bias is still a pervasive sentiment in our state all these years later.

We want to live in our communities, and it is our right to live in our communities. Many of us actually work, volunteer, and contribute to our communities in countless ways. It is the duty of the state, to comply with the Olmstead Decision and provide necessary community supports. That includes access to waiver nursing services. Per the ADA.gov website, "budget cuts can violate the ADA and Olmstead when significant funding cuts to community services create a risk of institutionalization or segregation" (5). The website also states,"if providing alternative services, public entities *must ensure that those services are* ***actually available*** *and that individuals can* ***actually secure them*** *to avoid institutionalization" (5*). Currently in Ohio, waiver nursing services are not usually available, and many individuals are not able to secure those services. There are many individuals and their families who have been searching for medicaid waiver nursing providers for several years.The Ada.gov website also asserts, "a plaintiff could show sufficient risk of institutionalization to make out an Olmstead violation if a public entity's failure to provide community services or its cut to such services will likely cause a decline in health, safety, or welfare that would lead to the individual's eventual

placement in an institution" (5). In other words, Ohio is walking a fine line by failing to ensure that Medicaid personal care aids and Medicaid nursing providers are actually available to those of us with disabilities. Waivers look great on paper, but when you cannot actually access the services, due to lack of providers in the field, they are nearly useless.

It is also much cheaper for the state to support us living in our communities, than financing lengthily hospital stays and institutionalization. What many in our Nursing Crisis Advocacy Committee have pointed out, is that when some of these individuals are hospitalized, they are admitted right to the ICU due to their complex needs for care. It is absolutely cheaper to support these individuals in their homes, than it is to pay for ICU level hospital stays, for months at a time, which occurs when HCBS nurses cannot be found, due to Ohio's extremely low nursing reimbursement rates.

It is time for Ohio to move from the dark ages, and pay both HCBS nursing providers, and direct care workers, a fair and competitive living wage. At a minimum, we need to see Ohio catch up with Kentucky, the lowest paying surrounding state, and increase Waiver Nursing wages another $10-15/hr to bring nursing reimbursement rates up to $39.00/hr. If we want to be competitive, and in line with the other surrounding states though, we need to raise reimbursement rates to $46/hr for Independent RNs, $38.52/hr for Independent LPNs, $52/hr for Agency RNs, and $46/hr for Agency LPNS. When you compare this request to rates in surrounding states, I think you'll see it's very reasonable. Unfortunately, at the proposed 19.9% increase in the budget, we are far from where we need to be as that only brings rates to $35.78/hr for Independent RNs, $29.94/hr for Independent LPNs, $44.36/hr for Agency RNs, and $37.50/hr for Agency LPNs. Again, please refer back to the included Medicaid Nursing & LPN Rate Per Hour Comparison Chart to really put things into perspective. I have added the proposed 19.9% increases for easy comparison. Of course, we would still like to see direct care aide wages reach that $20/hr, as well. Please ensure that a reasonable percentage of the agency rate increases will go to their employees. We'd also like to see an end to the higher base rate and lower unit rates in Ohio and instead see a fair, livable and competitive wage for all hours of work, for both nursing providers and direct care aides.

It's very important to understand that we need parity of wages across all three waiver systems – the Department of Developmental Disabilities, Department of Medicaid, and Department of Aging. When wages are only increased for one of these three systems, as often happens on the DODD side, it makes it that much harder to find providers on the Medicaid side who will work for much less. Some do not realize that many of us with developmental disabilities, actually end up on Medicaid waivers. Even when we qualify based on disability before 21, we are denied DODD waivers. As such, a significant portion of those of us with Developmental Disabilities often end up with less access to certain services compared to our peers with the same disabilities.

Pay is not the only issue. Like direct care aides, Medicaid HCBS nurses do not receive vacation time, sick pay, health insurance, retirement, shift differentials, mileage reimbursement, or opportunities for advancement. The enrollment process is difficult for

providers. The various rule differences and pay rates between all three waiver systems is complicated and confusing. There is a lot of work involved when it comes to keeping up with yearly training, maintaining lots of documentation, and staying current with all of Medicaid's rule changes. Managed Care Organizations are allowed to pay providers less than the already low standard Medicaid rates, and they do. These rates vary per provider under the same MCO. This needs to change. Paying providers even less than the already very low Medicaid rate is entirely unreasonable.

Providers are regularly forced to go without pay due to the length of the enrollment process, the time it takes getting contracted with managed care organizations, or due to systemic billing issues, and glitches in new systems. Our providers are still trying to recover from the Pay Crisis caused by the switch to Medicaid's new billing system that began in February. There are still people who haven't been getting paid properly and accurately for the time they have worked. We have lost more providers due to this, when we were already in a provider crisis to begin with, further reducing the already limited access to care. I've said it before, and I'll say it again: It is completely unacceptable, in a field that does not adequately pay providers in the first place, to stop paying them at all or force them to go without pay for weeks or months on end. Raising the reimbursement rates will have a reduced impact when Medicaid or MCOs, often fail to pay providers at all. With these pay issues, clients who already didn't have enough providers to care for them to start with, are being put in crisis situations that risk their lives. Even prior to this current pay crisis, near 30% of survey respondents, who are on waivers, have been left without care for weeks at a time (6).

On May 4th a question was asked about implementing certifications for providers. It's important to realize the negative impact that would have. Making the enrollment process more difficult by adding new certification requirements will only discourage providers from entering this field even more. Adding more bureaucracy to an already difficult process of becoming a provider, will only make things harder for everyone. Please realize that it's not the training that makes someone a good provider, it is the care they have in their heart, and listening to the needs of their client. Additionally, clients' needs are very individualized. A basic training certification can't adequately cover people's actual needs or the way the client needs things done. It would just be another unhelpful hoop that providers would be required to jump through. I've been through a lot of nurses in my time of having a central line. Nurses that have their training and certification and yet the majority of them do not know how to follow sterile protocol when handling a line, and as such, they cause infection and risk my life. It's even worse in hospital settings. Often family members do a better job than nurses because they truly care and have seen the negative impact of line infections in the past.

Ohio is ranked 6th nationally in the size of its aging population and it's expected to see a 43% increase in the number of older Ohioans with severe disability by 2030 (7). The odds are, that one day YOU will be in the position of requiring home aides and nurses to survive – as you age, recover from surgeries, or whatever the case may be. These programs are on the brink of collapse. If we don't act now, there won't be aides and nurses left when you need the care, or when a loved one does.

In closing, most people with disabilities want to remain in their homes and communities (8) – that is our legally protected right – and yet Home and Community Based Services remain largely underfunded. It is also significantly cheaper for disabled people to live in their homes and communities than in expensive institutions (8). What people with disabilities want is disregarded time and time again, while money keeps pouring into the institutions that we desperately try to avoid. Instead of investing in expensive institutions, it's time to invest in Medicaid HCBS Nursing Providers, Direct Care Workers, Disabled lives, and Home and Community Based Services. It is time to pay HCBS Nursing Providers and Direct Care Workers a higher wage that more accurately reflects the difficulty and importance of their profession. This truly does make the most sense for everyone.

Thank you for your time today, Chairmen Dolan, Vice Chairman Cirino, ranking Member Sykes, and The Senate Finance Committee. I would be happy to answer any questions via email.

Respectfully Submitted May 25, 2023

Georgie G. Elson
Disability Advocate
MyCare Waiver Recipient through ODM
Co-Chair of The Ohio Nursing Crisis Advocacy Committee
georgie.g.elson@gmail.com
937-564-2433

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