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HOUSE OF REPRESENTATIVES

COMMONWEALTH *of* PENNSYLVANIA

House Democratic Policy Committee Hearing
Disability Summit: Caregiver Workforce Crisis

Thursday, September 14, 2023 | 3:00 p.m.

Representative Joe Hohenstein

OPENING REMARKS

3:00 p.m.

Rep. Joe Hohenstein (D-Philadelphia)

PANEL ONE

3:05 p.m.

Michael Anderson, Legislative Advocate
Arc of Pennsylvania

Nakisha Steed, Life Skills Associate
Elwyn

Q & A with Legislators

PANEL TWO

3:30 p.m.

Jessica Ruiz, Advocate, Entrepreneur
Robert Rodriguez, Partner/Caregiver for Ms. Ruiz
Shelly Harris, Caregiver

Latoya Maddox, Senior Independent Living Specialist
Liberty Resources, Inc.
Ronica Adams, Direct Care Worker

David Janick, Consolidated Waiver Recipient
Lisa Scanlon, RN, Mother/Caregiver for Mr. Janick

Q & A with Legislators

Testimony by Michael Anderson before Rep. Hohenstein
on DCW Crisis (September 14, 2023)

Thank you Representative Hohenstein and colleagues for this opportunity to talk about the personal care attendant crisis. (By the way, some people call these employees direct care workers, others call them direct support professionals. I prefer the term personal care attendant because it more clearly describes what they do.)

My name is Michael Anderson. I have cerebral palsy. I am currently enrolled in Community HealthChoices, which is a Medicaid waiver program primarily for people with physical disabilities and older Pennsylvanians. I rely on personal care attendants funded by the waiver for all of my activities of daily living – taking a shower, getting dressed, eating, going to work, going to concerts, going to sporting events. Good attendants are essential for me to live a happy and productive life in the community.

Unfortunately, good attendants are getting harder and harder to find.

I have three main points to make for you. First, not all personal care attendants are created equal. There are two systems in Pennsylvania that finance direct care workers. The first is for people like me, who have either physical

disabilities or who are older Pennsylvanians. That program is run through the Office of Long-Term Living (OLTL). The second is primarily for people with intellectual disabilities or autism. That program is run by the Office of Developmental Programs (ODP). Personal care attendants who work under the ODP program are often paid substantially more than if they work under the OLTL program. That puts people like me at a real disadvantage.

Also, under the ODP system, personal care attendants can be paid a higher salary if the people they are working for require a higher level of support. In the OLTL system, there is no such system of variable wages.

Second, all personal care attendants need to be paid a livable wage. I have lost many good attendants just because the wage rate they receive is too low. It's hard to keep them working for me at \$12.50 an hour when they can get \$18 an hour working for Amazon or Target.

Third, the Commonwealth needs to get more involved in ensuring that personal care attendants are paid a liveable wage. Under Community Health Choices, managed care organizations receive a flat fee to cover all the services needed by people enrolled in their program. The MCOs, in turn, decide what reimbursement rates to offer the direct care agencies who will actually hire the people who

work as personal care attendants. After accounting for their own overhead, those agencies then decide the hourly pay rate for their employees. At no point does the state of Pennsylvania intervene in this process and require a minimum salary for direct care workers. And that's why salaries can be as low as \$9 per hour and never higher than \$13 per hour in the OLTL waiver program.

Under ODP's program, the state at least sets the reimbursement rates for providers, based on the level of support needed for individual clients. While this does not guarantee any particular wage for personal care attendants, you can at least know that if the reimbursement rate is raised, this will probably result in correspondingly higher wages for the workers. But it would be more reliable for the state to mandate that employees receive at least a minimum level of salary. Wage rates for personal care workers under ODP are still too low, even if higher than under OLTL.

In conclusion, I want to emphasize that we have two different reimbursement systems for personal care attendants in this state. Both systems have their problems, and both systems need to be improved.

Thank you for your time.

Kenneth Ritter

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Kenritter23@gmail.com

I am writing this regarding my son, Nicholas Ritter. Nicholas is twenty years old, and was diagnosed with autism and intellectual disabilities at the Children's Hospital in Pittsburgh when he was three years old. We live in Neshannock Township, In Lawrence County PA. I had him enrolled in early intervention and he went to the IU4. Transportation was always an issue with Neshannock School District. They would pass the responsibility on to other school districts, and they never followed the Functional Behavior Assessment Plan on the school bus. They would never fill out incident reports, they would just call me and say they were no longer able to transport him and that a different bus would be transporting him.

The IU4 and the school district would not do anything that was in the IDEA. As a result, I decided to get help from the PEALS center in Pittsburgh and by calling the Department of Education. For around three years I would call them regularly and could not get any help. During this time, he had a consolidated waiver and services were very hard to get. I had to hire an attorney to fight the school district, and after years of fighting them, he was placed at the DT Watson Institute in Pittsburgh.

In the meantime, he was supposed to be getting services through the waiver for behavior specialists and TSS. The services provided never fulfilled the hours he was supposed to get weekly, neither at home nor at school. When he was 8 years old his mother passed away and it was very hard to find a daycare or babysitters to watch him when he was not in school.

I found a daycare center that did a good job with him, but after Nicholas was age twelve he could no longer attend daycare and this made it once again difficult to find the proper care for him. Through the consolidated waiver an agency would send a person to our home to take care of him and get him ready to go to school. This person did not work out because he was unreliable. He was incompetent, never on time, and brought bed bugs into our house.

This whole time I have had a supports coordinator from the Human Service Center in New Castle. The county said that they were the only agency that was contracted to do services in Lawrence County. I later found out that this was not true, and that any agency can do it. When Nicholas was sixteen I did not have the resources to take care of him at home, so I placed him in the care of Passavant Memorial Homes' Baldwin B Youth Program for Children with intellectual disabilities and autism. I would continue to bring Nicholas home on the weekends and on Holidays (Passavant was paid during the times he was with me through the ODP). For the next five and a half years, I had to constantly fight with Passavant Memorial Homes to try and get them to properly take care of him. They claimed to have a program to help work with these kids, but when I asked them about the program they could not give me any details. During Nicholas' time there, his health and behavior progressively worsened. He was not properly bathed or fed, and as a result, his acne became much worse and he gained weight. They had no menu and would feed him simple things like soup and microwave dinners. They did not take him anywhere in the community or to exercise (I bought a pass for them to take him to the YMCA). They would send him home wearing clothes that belonged to other residents. He would come home with poop stuck on his butt and in his underwear, as if they had not properly wiped him. I would bring him new clothes all the time that would frequently end up missing.

His behaviors were also negatively affected during this time. He began to have night terrors, and I was never informed on how bad they actually were. He would wake up in the night and pound his head on the wall and scream. They did not attempt to find out what was causing this, they only put a pillow between his head and the wall. He came home a few times with scars on his head. I called Governor Wolf's office, Lt. Government Fetterman's office, the Department of Human Services, and ODP. They never filed an incident report. The ODP told me that they only had to file an incident report when the police or an ambulance is called. These are just a few examples of the things that went on at Passavant Memorial Homes. My other son is helping me type this up, because I am not great with computers, but I could explain these things in much better detail in person or over the phone.

Up to this point I tried to get Passavant Memorial Homes to bring in a behavior specialist and a worker for him and they would not do it. The ratio was three staff to four kids, and all of the children there exhibited behavior as bad as Nicholas'. When I would go to pick him up on visits, I would ring the doorbell and I was almost always greeted by one of the residents and not a staff member. The staff members would sit in the living room, usually on their phones and watching what they wanted on tv while the kids ran wild. I called Passavant and complained many times about this and nothing was done. I also called ODP, as well as his supports coordinators, to tell them about what was happening at Passavant, and they did nothing. I have the notes from the supports coordinator to prove it.

During the COVID lockdown, he never went outside for the whole year. They have a large campus and could've at least taken him for walks but did not. This contributed to his weight gain. They also did not do anything for him in regards to his schooling (virtual) during this time. The school offered to send materials home for him and they refused to accept them.

In 2021, Passavant called me and informed me that they were shutting Baldwin B down. They said that I had six weeks to find a new place to take care of him, or that I would have to bring him home. I could not take care of him myself at this time because I was not yet retired. I later found out through the Disabilities Rights Network that they could not have thrown him out until I found an appropriate placement for him. I could get no help from the county or the supports coordinator. Passavant called me to inform me that they had a home available for him in the Marratta House in Aliquippa, PA.

When I went to check out the house, they put on a big show and had people that do not actually work at the house explaining to me their program. They were supposed to transition him into the house, and to my knowledge, they never did. From day 1, his behaviors became worse in Maratta. I called there many times to find out what was going on and they would give me vague answers. I went to the house on a few occasions. I asked house manager Gary Hickman what was going on, and he said that Nicholas was breaking things frequently and smacking his head off of things. I asked him if Nicholas was going to the bathroom okay and he said, "I think so because all of Nicholas' underwear has shit on it." By this time, I was calling the Office of Developmental Programs, the director of the Pennsylvania Department of Human Services, and his supports coordinator many times. They failed to get him to school, doctors' appointments, and blood work. He was on a Hopewell Bus because Neshannock School District would not go to Hopewell to get him, and the Hopewell bus was not equipped to handle him. His behavior on the bus was so bad that I had to become the bus aide and Neshannock had to start transporting him again. Maratta Homes would let him run to the bus by himself with no escort, which they were not supposed to do. Sometimes I would have to knock on the door for 5 mins or more before they let him in off the bus. It became so bad that we set up an appointment with a

psychiatrist that I was supposed to attend. They went behind my back and did the appointment over the phone and prescribed him Seroquel. The Seroquel made his behavior even worse and school district would attest to this. I continued to file complaints to the Office of Developmental Programs. They did nothing and claimed that they had internal investigations. They investigated themselves, essentially letting their office workers do the paperwork instead of the people who were in the home. I called Adult Protective Services and the State Representatives, and they did nothing. I sent Representative Joe a picture of the cuts on Nicholas' head and his hand. I called the Hopewell police and Passavant told them that they would have to talk to their attorneys before they could tell the police what had happened during the incident. There is way more misconduct that happened with Passavant and Marratta, this paper is just scratching the surface.

In January 2022, he was on a home visit when Passavant called me and said they had a COVID outbreak and that I had to get him tested. He tested positive for COVID and I couldn't send him back for 10 days. It was at this time that I removed him from the program at Passavant and kept him at home because of all of the trouble that had happened.

I began to contact the supports coordinator to get services in my home through home and community (which is in the waiver). They could not find any services for him. I began to call places on my own (which is the supports coordinators job) and by July I found two places and neither place said they would help him wipe after using the bathroom. I continued to call the Office of Developmental Programs and talked to a lady named Laura (412-565-5129). I tried to get her to help me get services and have Lawrence County have the supports coordinator and Lawrence County give me a list of agencies that provide services. They did not help me. Finally after arguing with them many times, they got services for Nicholas and the services began. His

waiver calls for 96 hours of service per week and I was only getting 12 hours of service per week.

After twenty months of having him home, I am still only getting fifteen hours a week of outside services. My son and I had to join the agency DON Services and begin working for them taking care of Nicholas. At one point, I found a group home in Hermitage that did respite and had group homes. I called my supports coordinator and told her about it, and she was unaware that the home even existed. I asked her and a lady from the county to go up and check the place out. They did, and they said it was fine. Also, I found out that they had two people in a group home with the same agency and one of them was getting respite from Lawrence county. They approved Nicholas to go there for respite on Saturdays for six hours. I wanted to transition him into the group home. So I got the ODP involved, and they said they had a transition program available. After they got involved, Nicholas went to the home for three Saturdays and visits were stopped because the home was not in compliance with any of the ODP's rules and the home was put on probation as a result.

In conclusion, there are many issues with the Disabilities Programs available to me in Lawrence County. My first issue is that these group homes are largely unregulated. There needs to be people from an outside agency holding these homes accountable to the law and ensuring that the people in these homes are receiving the proper care that they need. Something needs to be set up so that outside investigators with no ties to the state of Pennsylvania or to the group homes themselves can go into these group homes unannounced and see what is actually going on. Group homes should not be allowed to investigate themselves, and all of the homes should have video surveillance to combat cases of neglect and abuse. They need to be stricter when it comes to incident reporting. The workers must be attentive to the people they are taking care of.

They should not be able to just sit on their cell phones or watch what they want on the television. The food served should be healthy and they should keep a menu of what is served each day and make that menu available to the parents/guardians of people in these homes. The supports coordinators need to be able to provide the consumer with resources about what types of care are available for disabled people. At least in Lawrence County, none of my supports coordinators were able to give me the information I needed and I had to find the information on my own. Nicholas graduates from school this year and I am currently looking for a day program. The supports coordinator and the county were unable to provide me with a list of any day programs that are available to him.

My final comment is that I am sixty-five years old, a single parent, and that when I die I want to be sure that wherever Nicholas goes he will be properly taken care of. So far, the state has spent tens of thousands of dollars on these programs, which have been largely a failure. The last year he was at Passavant they spent 120,000 on him in a year and it was a complete disaster. The group homes are supposed to be non-profit organizations, and all of the ones I talked to said that they don't want to transition him into the home because they can't keep a bed open for him. These homes are making millions of dollars off the backs of people who cannot even stand up for their own rights. Nicholas has an ISP and a PUNS and they cannot even keep these updated properly. I have the phone number for the ODP Supervisor (412-880-0594), and Bryan has blocked me so that every time I call I have to use someone else's phone. The same is true for Michelle Anthony (412-209-4459), another supervisor with the ODP.

I have much more to say and would love to set up a meeting with the ODP, the head of the Department of Human Services, or even be able to testify whenever the ODP has hearings about what needs changed. My contact information is listed at the beginning of this letter.

Sincerely,

Kenneth Ritter

Good afternoon,

I would like to thank representative Joe Hohenstein for being a phenomenal ally to this disability community and asking me to testify at this hearing.

I have used home community-based services since I transitioned out of the nursing facility in 2004. Almost 20 years ago, wow how times have changed, sadly not much for the better. I do not use the consumer directed model because all my friends and trusted family members have full time jobs, and my schedule is not rigorous. If you get the gist Consumer directed model is when the consumer hires and fires all attendants. As of right now Agency model works best for my situation. I'm a mother, work full time and am very involved with advocacy with the disability community at the local, state, and national levels. My attendants help me in every aspect of my life which includes but is not limited to: bathing, dressing, undressing, toileting, feeding, etc... My attendants are hired through a Personal Assistant Agency. The agency pay my attendants. I ended up having no choice but to hire my sister because at the beginning and height of the pandemic my case was left unstaffed on the weekends. Most agencies start attendants at \$8-\$10 per hour. To accumulate living wages and leisure money attendants must work for multiple consumers or even have another job. When I speak of accumulating a living wage, I mean having money to pay rent, mortgage, and other living expenses. Let alone paying for health insurance. Health insurance premiums are costly and with the wage attendants bring home after taxes they cannot foot the bill for living expenses and benefits. My sister stated, "I makes too much money before taxes, I don't qualify for MA. But after taxes are taken out, I cannot afford to pay a premium and rent." Oh, let's not forget attendant dread the need to call out, because a lot of agencies do not offer PTO, and other benefits, my attends just lose money for that day. Yes, I know minimal wage is supposed to increase to \$15 per hour by 2026, but is that truly enough to combat the increase in housing costs, inflation, and increase of premiums which happens almost every year? No...I truly hope you listened to me and we create a better system for livable wages, ways to combat retention so consumers are left without an attendant, I can only speak for myself, but 20 years outside an institutional setting has been glorious for me. Going back in would be devastating not only for me but for my son, family, and friends Thank you!

