

Across Ohio: Direct Care Crisis

Accessible Version


#EveryoneDeservesCare

Our **Everyone Deserves Care** series shares a sampling of the stories of Ohioans impacted by the direct care workforce shortage.

This version serves as an accessible PDF that can be used by screen-readers and others who otherwise cannot use the interactive platform. We hope you will read and share these stories to see how the direct care crisis is affecting all of Ohio.

Each story will share an image, the story from their own perspective, and the location of the constituent in relation to our legislators, organized in order of Senate District number.

Special thanks goes to Disability Rights Washington who helped us to make this project a reality with their advice and expertise.



Across Ohio: Direct Care Crisis

Table of Contents

Senate District 1

- Latisha's Story: **Pgs. 3-5**

Senate District 2

- BC's Story: **Pgs. 6-8**
- Allie's Perspective: **Pgs. 9-11**

Senate District 5

- Cynthia's Story: **Pgs. 12-14**

Senate District 7

- Daniella and Roxanne: **Pgs. 15-17**

Senate District 9

- Vicki's Story: **Pgs. 18-20**

Senate District 10

- Cara and Corey: **Pgs. 21-24**
- Maria's Story: **Pgs. 25-30**

Senate District 15

- Allie's Story: **Pgs. 31-33**
- Jynette's Story: **Pgs. 34-36**

Senate District 16

- Kevin and Carolyn: **Pgs. 37-40**
- Christine's Story: **Pgs. 41-43**
- Julie's Story: **Pgs. 44-46**

Senate District 17

- JW's Story: **Pgs. 47-49**

Senate District 20

- Luke and Heather: **Pgs. 50-52**
- Robert's Story: **Pgs. 53-55**

Senate District 22

- LC's Story: **Pgs. 56-57**
- Marcus and Cindy: **Pgs. 58-60**

everyone
deserves
care

*Ohio House, District 81, Representative James Hoops
Ohio Senate, District 1, Senator Rob McColley*

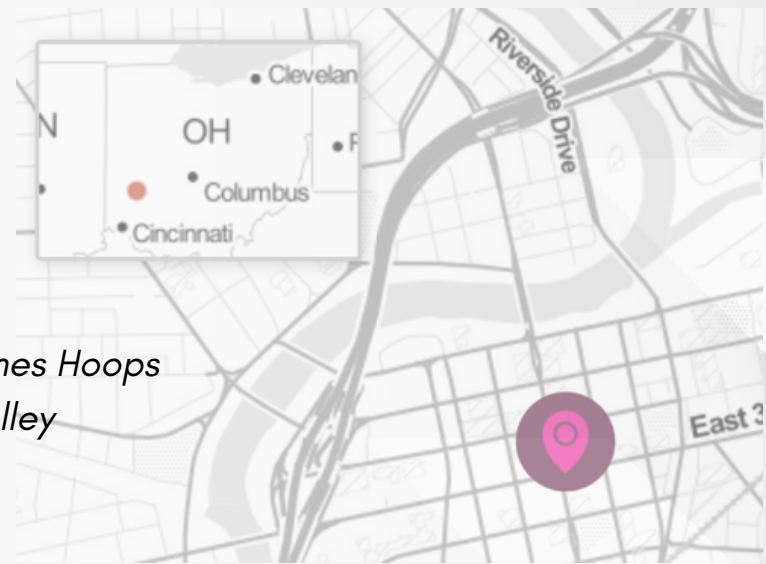
Latisha's Story

Latisha introduces herself as an African-American woman with mild to moderate cerebral palsy who is the second oldest of eight sisters. She graduated from Meadowdale High School for International Studies on May 31, 2003, and from the University of Vermont LEND (Leadership Education Neuro Developmental Disabilities) Program on May 9, 2022.

From an early age, Latisha has been a fierce advocate, both for herself and for others. During her childhood she did not have a stable home until the age of 12 nor the accessibility her disability required. Latisha reached out to a teacher because she felt she was not being properly cared for. Her teacher encouraged her to share her story with the school services coordinator. She was confident to share her story because she had documentation to prove her negative experience. Latisha and the coordinator had a three-hour conversation that resulted in her getting put on the emergency status list. From there, she was able to start the provider selection process.

Today, Latisha receives daily living, transportation, and financial support from her direct care workers. In order to receive all the care she needs, there must be available staff that can assist her. She enjoys living independently because it offers her the freedom to go where she wants. Moreover, it allows her to be active in her community.

Latisha is a member of the Breaking Silences Advocacy Committee. The Breaking Silences Advocacy Committee is a group of individuals with disabilities who advocate for structural change within disability systems.



She is also involved in the committee's peer support group that offers individuals with disabilities community support and resources to handle difficult situations. The support group also serves as a safe space for individuals to come together to talk about personal problems.

Latisha volunteers as an Ohio State Ombudsman associate. In this role she advocates for the rights individuals in the Sanctuary Nursing Home and provides a listening ear if needed. She also serves on the Ohio Olmsted Taskforce Direct Care Crisis Work Group, where the group works on solutions to the crisis while educating legislators and lawmakers. Additionally, Latisha holds a seat on the Ohio Provider Resources Association (OPRA) Advocacy Committee, which assists individuals with disabilities on how to get more involved in advocacy work. In 2019, Latisha advocated for herself to get an automatic door opener and other wheelchair accessibility accommodations in her apartment with assistance of the Miami Valley Fair Housing Center in Dayton, Ohio. They proceeded with filing an accessibility discrimination case, which they won in April of 2022.

Latisha has grown concerned because the people that assist her have children and have to drive back and forth. With the increase in gas prices she is afraid of losing staff because travel has become more expensive. She recounted how she has an assistant with three children who is looking for another job because of high gas prices. She commented that at ten dollars an hour her assistant is struggling to put gas in her car. She believes she is going to lose staff because the agency does not want to help the workers or offer assistance. This has created the fear that in the future she will not have staff and will be forced to go into a nursing home.

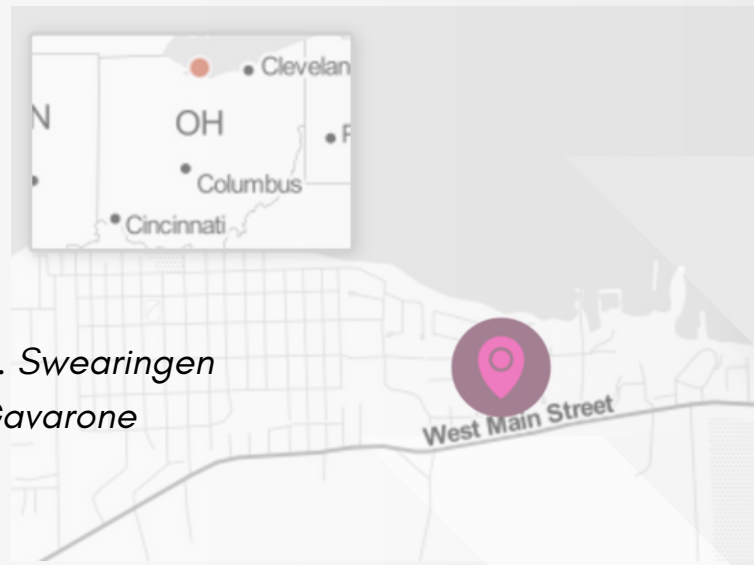
Latisha wants people to know about the emotional damage that can take place when an assistant is let go by the agency. Latisha says she has experienced this firsthand on two occasions. She had one assistant that helped her for three years and then she was let go.

The agency told her assistant she needed medical training and then she could come back, but she did not. The second instance was for the same reason and also resulted in her assistant not returning. Latisha has become good friends with her assistants, so it hurts when they cannot return. She thinks management needs to take the client's feelings into consideration and think about the impact that changing assistants will have on the individual.

Latisha believes that better wages would help to resolve the crisis. Furthermore, direct care workers should receive gas cards, bus passes, and increased gas mileage pay. There should also be better accommodations for workers, such as a substitution list and benefits for staff, especially for those that have children.

In addition to advocating for better treatment of direct care workers, Latisha also wants to advocate for removing annual caps for equipment and services for people on Medicaid. For instance, having one dental care trip a year or receiving one new wheelchair every five years is often very limiting and not enough to meet people's needs. She wants people who use services to have the ability to get them when they need them, especially during emergency situations. Increasing investments to support people in their communities is needed to help people live their best lives. These investments are necessary along with improving the direct care workers service systems to ensure high quality care for individuals.

-Transcribed by Tavis Daluz-Cates from Latisha Martin



*Ohio House, District 89, Representative D.J. Swearingen
Ohio Senate, District 2, Senator Theresa Gavarone*

BC's Story

When BC's son, CC (now 34 years old), was diagnosed with a Pervasive Developmental Disability (now known as autism spectrum disorder), she was not new to the disability world. As a special education teacher, she had experience in teaching children with disabilities. BC quickly learned that having a child with a disability is an extremely unique experience.

Being able to live independently in the community has always been a goal for CC and his family. "My goal was for him to live independently, be employed, and have community connections," BC reflects, "And that has not worked out very well. It's been a very long road."

CC is a social and friendly person. In high school he made a great group of friends who made him a part of their community. When asked, CC explained that he likes being an adult and living on his own. "I like having my own place, having spare time and alone time... I like to work out, run, exercise, and be with friends."

One of the main factors that has made CC's road to independence difficult is the shortage of direct care workers – people who can provide the support CC needs. Since CC started living independently, 11 years ago, their family has gone through at least 6 different providers. BC has spent hours combing through agencies and organizations to try and find providers. Papers and folders were cluttering their home as the search weighed heavily on her. Eventually the stress of combing through providers wore BC down, and she agreed to give the responsibility over to CC's Service and Support Administrator, or SSA. She hoped that doing so would make the process smoother for CC while causing her less stress.

BC recalled a time her family was having a particularly good experience with a provider agency. Her son had indicated that he did not like one of the agency's providers, but BC believed this was because the provider simply played on their cell phone most of the time. However, BC and her husband were crushed when they accidentally caught the provider verbally abusing CC on a front door camera. Unsure of what to do, but not wanting to lose CC's other provider and their relationship with the agency, BC called their local county board of developmental disabilities. She was not aware that the board employee was a mandatory reporter, and their family was subsequently dropped from the agency. "I've been trying to fight the good fight," BC states, "but there is always something. It's the upkeep."

Having providers who can help CC live independently is important both for BC and CC. "We might need a break from him, but also, he needs a break from us." CC enjoys having alone time, and being able to do chores on his own. BC recalled the time when CC started mowing the lawn on his own. "He was so proud that he was able to do that independently."

The stress of caring for CC falls on more than BC and her husband. Her other sons also feel the weight of CC's care. Like many parents of adults with disabilities, BC worries about what will happen as she continues to age. "We want to know that he will have a good place before we can't take care of him. I don't want it to get to that point." As CC ages, his parents have had more difficulty managing his behaviors. He has had several negative encounters with law enforcement officers, during one of which he was pepper sprayed by an officer. He has battled several addictions. CC used to get a weekly allowance, which gave him more freedom, but as his behaviors increased, his family was forced to pull back some of his resources. "We want him to have independence and trust him... we want him in a community where he can walk to get coffee, to see his friends, or go to the gas station."

When asked how a lack of care for CC has impacted their lives, BC responded that it impacts everything. “We don’t have as much freedom as we would like as we age.” Despite their lack of care, BC still considers herself lucky. She has a great group of friends she can rely on and believes that regular exercise is crucial. But more providers and more care will become more and more critical for CC and his family as his parents continue to age.

When asked what changes need to be made to improve the direct care system, BC was quick to share ideas. She hopes for increased wages for providers, and a more robust education and training program for them. In particular, she believes providers need more preparation in dealing with challenging behaviors. BC also wants to see an increase in some county housing programs. “If they don’t have statistics about how many families are like us, how do they know how much money and resources to use?” She is a firm believer in change from the ground up. “Give money to the local levels, because they know their community better. They know what their community needs.”

Finally, BC wants to see a change in the waiver process. When CC was younger, he was kicked out of a group home. During that time, he was technically considered homeless, and therefore, qualified for the Individual Options (IO) waiver. The IO waiver has been indispensable for CC, but he shouldn’t have needed such extreme circumstances to get it, which is a product of a service system where demand far exceeds the level of services available and therefore has waiting lists.

BC doesn’t just talk about the changes she wants to see in the direct care system, she advocates for it. She has made numerous phone calls to her state representative and congresswoman, and attended yearly conferences to learn more about CC’s options. At the end of the day, she simply wants her voice to be heard. “If I have questions I go to parents in the same situation. They have the best suggestions, because we’re all in it together.”

everyone
deserves
care

Ohio House, District 42, Representative Derek Merrin

Ohio Senate, District 2, Senator Theresa Gavarone

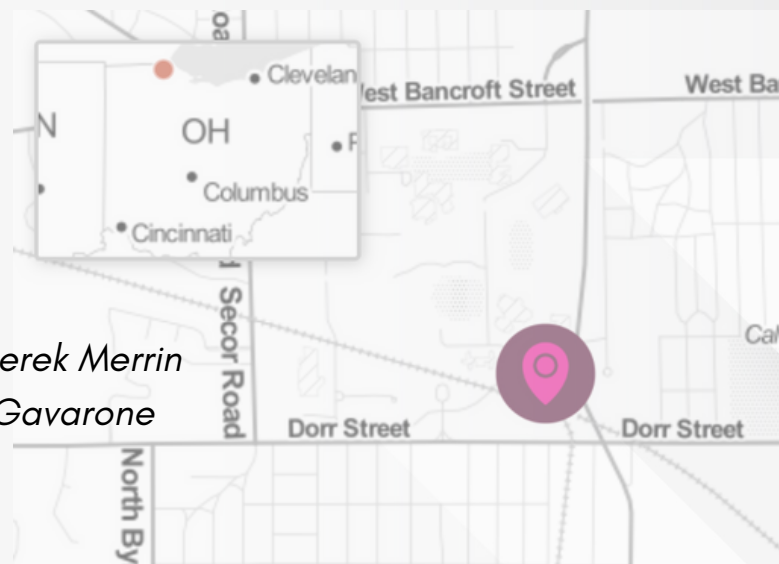
Allie's Perspective

Allie enjoys the simple things in life. She loves concerts, her service pup, and helping others. Her days are filled with life and love and just like everyone else, she needs help. Allie is a C5, C6, and C7 paraplegic, and requires around an hour and a half of care in the morning and 20 minutes of care at night. These services are covered by Ohio's Medicaid-funded waiver program and allow her to be a productive, happy person. Allie compares her relationship with her service providers to working as a team, for both of their benefit:

“At the end of the day, I'm just trying to do the same exact things that you're trying to do. I'm trying to wake up and be productive and take advantage of every part of the day that I can—in the best way that I can. Just like they need help in certain departments of their lives, I need help in these departments of my life. So, if we can just take that at face value and we can negate those needs for each other it just makes for an easier working relationship.”

Allie does not see herself as a typical boss towards her service providers, but rather recognizes the many benefits of interacting with those with different life experiences.

“You're not my worker, I'm not your boss. You help me; I'm going to help you gain perspective and see what it's like (living with a spinal injury). Something like this doesn't discriminate and something like this could happen to you or one of your people,” says Allie, while explaining her patient-care-worker relationship.



Allie's direct care struggles really began when the COVID-19 pandemic swept the United States. Her main provider was forced to step down from her position to protect her family, leaving Allie scrambling to find help.

"If nobody comes, I become a depressed nightmare. Without that extra pair of hands, I can't get out of bed," remarks Allie, while recounting her lived reality without direct care.

To reiterate, if no one comes in the morning Allie is stuck in bed all day. Without her morning stretching, her mobility is extremely low, making it unsafe for her to move around her own home. Allie is fortunate to live with her parents; however, as her parents have aged, it has become more and more difficult for them to assist her.

A frustrated Allie notes, "the point of the waiver program was for me to still be at home and not affect my family relationships."

Allie will usually have to wait for her friends to get off work to come get her out of bed. She expresses, "There's nothing worse than feeling completely powerless. I can't do it myself, and I'm at the mercy of a complete stranger or one of my friends."

Allie is proactive in the fight to retain quality care workers. She works hard to befriend them early on, not only to make their job more pleasant, but to try and prevent them from leaving.

Allie is a major advocate for spinal cord injury research. She has found that involving "her girls," as she affectionately refers to her care providers, increases their understanding of her life experiences. As a result, they become more invested in their work and their empathy towards those that they help increases. Allie believes this is a key part of long term, high-quality care.

But Allie also recognizes that more change is needed than just an increase in empathy. New care workers come to her extremely underprepared, with little to no real-world experience. One important shift she would like to see is an increase in paid meet-and-greets to allow providers and people who need direct care to get to know each other before officially starting work. “I just wish for a little more compassion and humanity ... At the end of the day these are human beings that you are helping start their day, which is a part of their life.”

Despite the challenges of the direct care work crisis, Allie feels lucky: she recognizes her privilege compared to others with less support, access, or income.

“I’m very fortunate. I get to take a shower every day, get out of bed every day. I get to go outside and count the cars and watch my dog.”

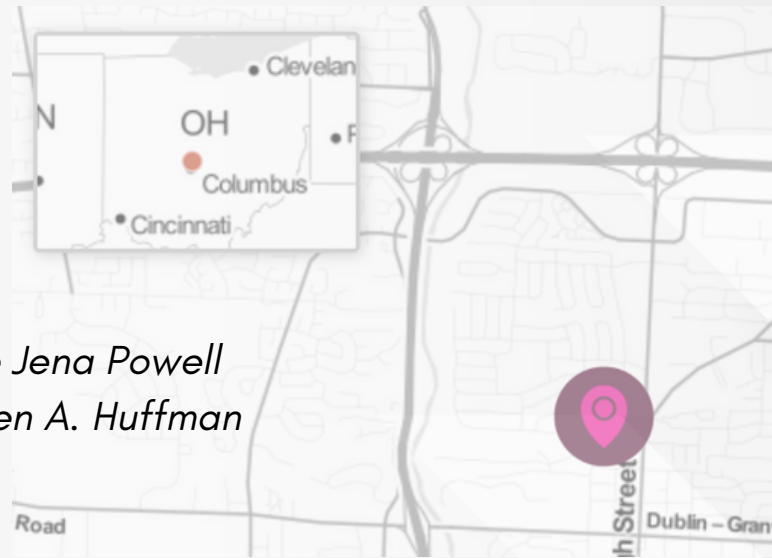
Service providers keep people who need direct care, such as Allie, out of nursing homes; they play an integral role in the lives of disabled people. Through her spinal cord injury support group, she has met many people with negative nursing home experiences.

“It scares the living daylights out of me to think what life would be like [if I could not be at home],” says Allie.

Direct care workers allow Allie to stay in her home and community, and it is important to her well-being, that her life stays this way. “My days are filled with life and love with my service pup.”

everyone
deserves
care

Ohio House, District 80, Representative Jena Powell
Ohio Senate, District 5, Senator Stephen A. Huffman



Cynthia's Story

Cynthia Fox knows firsthand just how starkly different life is with and without direct care workers, particularly, with and without the independence these workers provide.

She became quadriplegic at age 22 and spent the first 10 years of her life as a disabled woman in a nursing home. Her parents were not equipped to navigate her care, which includes a ventilator, and the only nursing home that would take ventilator patients was half an hour away from her hometown.

“I really thought I was going to die there,” Cynthia says. In many cases, the staff to consumer ratio in nursing homes is just not enough to provide adequate care, especially for those with complex needs. Things changed when Cynthia met her boyfriend, Steve, and the two decided to move in together.

“When I got to my apartment, I was so unfamiliar with being out of the nursing home and independent living out in the community it was like a whole new world,” Cynthia remembers. “I said to my nurse are you able to wash my hair every day? And she laughed and said, ‘Of course!’ But that was a luxury to me.”

Cynthia and her caregivers quickly found their routine and became like a family, working together like a well-oiled machine.

Aside from assisting her with daily living tasks like transferring in and out of bed, eating, bathing, and toileting, her care workers also empowered her to build a life in the community. She got to go shopping, attend family gatherings, she went to her five-year class reunion, took her dogs to training classes, developed crafting hobbies, started volunteering with a dog rescue by helping with their fundraisers, and more.

“It was just like a whole new world. I was on a vacation that didn’t stop,” Cynthia says of life in the community versus in the nursing home.

When Cynthia has the full care that she needs, it requires a team of six to seven caregivers. These days, Cynthia is down to just three nursing assistants and the support of her boyfriend, who is also a nurse. One of her nursing assistants has been with her for 10 years.

While Cynthia’s small but dedicated team is able to provide her care, she worries deeply about the sustainability.

“We’ve all grown to age together,” she says. “I see the toll it’s taken on them physically and mentally. I see that turning me in bed is hard for my aide. Lifting me up out of my wheelchair is difficult for Steve. Every day even if I’m having a good day, or it’s always in the back of mind that somethings going to happen and they’re going to try to put me back in the nursing home. I have this fear every day.”

Every day I’m afraid that I’m going to get an email from [one of my aides] saying that she’s gonna quit because the pay is not enough,” Cynthia says. “We get along great. We have fun days together. We never get in arguments and I don’t want to lose her, but on the other hand why would she not want to quit? She’s underappreciated in the eyes of Medicaid and I feel terrible for her.”

In Cynthia’s world, direct care workers make life happen. And she strongly believes that this valuable job deserves more appreciation and recognition – increased pay, quarterly incentives, gas cards, and benefits are a few concrete ways she believes society could take those steps.

“[Direct care workers] are my arms and my legs. Without my nursing assistants I would just lay in bed and be a body.”

“I want whoever reads my story to know that I just never, ever, ever want to go back into a nursing home. I won't have my job. I won't have my animals. I won't have my boyfriend. I won't have my home. I won't have my livelihood. It will be the death of me. I will do anything and everything I can to not go back in. It's just not a place for young people to be or people with disabilities.”

“People with disabilities are people, too. We depend on others, but we are just like able bodied people. Sometimes I think that we're not looked at like we're worth anything. We're not trying to drain society, drain money, or drain Medicaid by our care needs. People with disabilities, we can work. We pay taxes, but without the people that are getting us up and helping us become independent, we cannot be members contributing to society.”

everyone deserves care

*Ohio House, District 27, Representative Rachel Baker
Ohio Senate, District 7, Senator Steve Wilson*

Daniella and Roxanne

Daniella is 28 years old, and she loves books, television, music, and spending time outdoors. She has RETT syndrome and lives at home with her mother, Roxanne. Daniella requires a high level of care as she is tube-fed, diapered, has no communication system, lacks functional hand usage and uses a wheelchair.

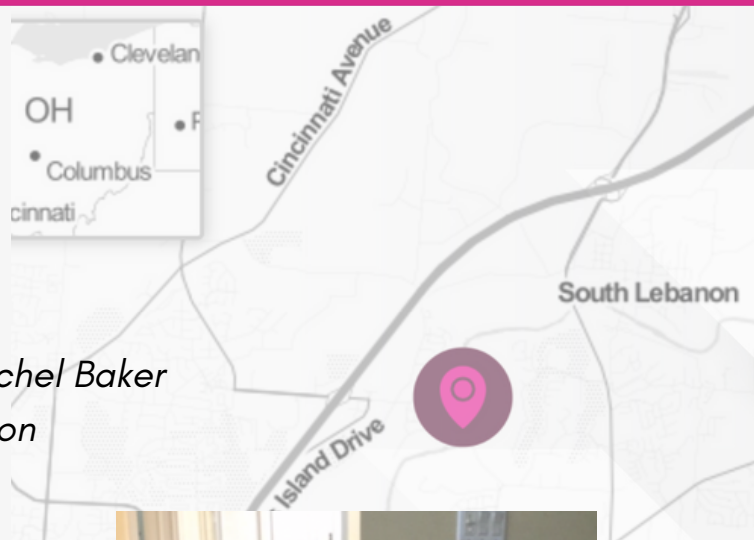


“Her days are very long because she is so limited in her abilities, and so she really spends most of her day watching television” shares Roxanne. Roxanne feels that sitting in front of a television for 8 hours a day is “a pretty low quality of life” for her daughter.

Roxanne does what she can to avoid Daniella sitting around, often reading to her and taking her for walks. However, Daniella would have a more active lifestyle if she received more direct care or could participate in an appropriate Day Program.

“To find somebody to do something with her or to find an activity for her to engage in has really been impossible,” notes Roxanne.

Finding care for Daniella has not always been so difficult. Roxanne shared the story of her initial request for services: she simply mailed a general inquiry to Montgomery County when Daniella was three years old. The response was prompt and Daniella was placed on a Medicaid-funded waiver program to receive 42 hours a week of nursing care.



Daniella remained on a waitlist for eight years before finally getting enrolled on a waiver in 2020. Even then, placement on the waiver was essentially meaningless as no providers were available. Roxanne was only able to utilize the waiver by providing employees to an Ohio Department of Developmental Disabilities-certified agency that would add them to their payroll and bill for them. If she does not provide employees, she cannot use the waiver.

She had found these employees before Daniella was on waiver, through Nextdoor and other social media platforms. Those aides worked on a private pay basis. In order to have them work for an agency, Roxanne often employs and pays the workers for additional work, such as cleaning her house, to offset the low wages paid by the agencies. Roxanne believes these additional payments were the only way to ensure that workers would continue to return.

Initially, the services Daniella received allowed Roxanne to continue working full-time. However, eventually Roxanne had to quit her job, as they began facing issues with Daniella's care. Roxanne ultimately decided that it was easier to quit work and care for Daniella herself.

However, Roxanne admits that her inability to work full-time has created hardships for herself and Daniella. She wishes that she could have continued to work to build savings.

Currently, Daniella has 1:1 aides for 4 hours per day to provide her care, and she is authorized for another 4 hours a day of nursing care. Roxanne notes that for the past two years she has only able to staff two nights a week of nursing care.

Roxanne wishes that people understood how hard it is to navigate the direct care system. However, the complexity of the system is not the only issue Roxanne notices. "To have a field where there are no benefits and no good compensation and to expect that people will work in that field and do a good job is a huge hindrance to both the people with disabilities and the people who want to help people with disabilities," comments Roxanne."

Despite the challenges, Roxanne notes, “Our care situation I know is a lot better than a lot of people.”

However, a new strain on Daniella’s care began when Roxanne was diagnosed with stage 4 cancer. Currently, her prognosis is approximately one year. Despite the fact that she is disabled by the cancer, Roxanne is unable to collect Social Security Disability Insurance because she has not worked in the past 10 years.

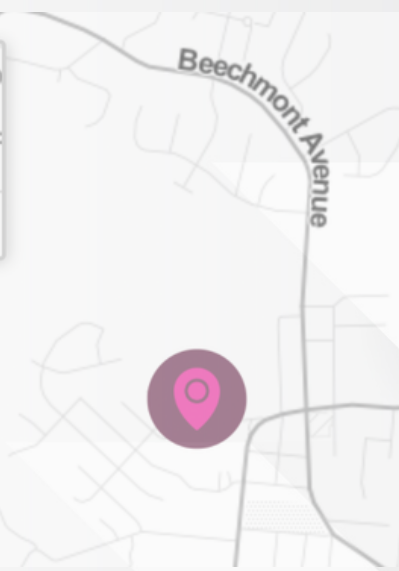
Roxanne worries about her symptoms getting worse to the point where she is unable to cover the unstaffed nursing shifts. “My bigger concern is that when I die, who is going to manage [Daniella’s] care and make things happen?” shares Roxanne.

Daniella’s father lives nearby and helps with Daniella’s care, but he is also older and has his own health issues that make it difficult for him to provide care for Daniella.

Roxanne has started to worry about Daniella’s future more because of her terminal cancer diagnosis. Roxanne does not want to place Daniella in a nursing home or move her to a private group home. Her biggest concern is continuity of care for Daniella: Daniella’s current aides have been with her for four years. “People knowing her is what makes her care good,” states Roxanne.

Due to these concerns, Roxanne is currently in the process of trying to figure out how to arrange a stable and consistent future for Daniella after she has passed away.

“That’s my biggest concern with the whole system – people can muddle by as long as they are alive and able, but gosh, what happens - especially to people who don’t have family, when their caregiver dies?”



Ohio House, District 24, Representative Dani Isaacsohn
Ohio Senate, District 9, Senator Catherine Ingram

Vicki's Story

Vicki Linder loves gardening. She loves her pets and having her daughter as her caretaker in the evenings. Vicki lives in Cincinnati, Ohio and is predominantly bed-bound due to multiple physical disabilities and thus dependent on the assistance of an aide to complete activities of daily living such as bathing, dressing, and feeding. Her daughter, an already overworked attorney, ends up working 80 hours a week when you include the care services she provides and has yet to be paid for.

Vicki also needs assistance with other vital tasks such as handling her finances, cleaning her home, and getting to doctors' appointments. Because of this, she is approved to receive numerous hours per week of consumer-directed services through Ohio's Choices Home Care Attendant program, available through MyCare Ohio and PASSPORT, both of which Vicki has tried using. These programs also assist with money management, correspondences, yard work, housekeeping, and other vital services related to independent living. All of these services are vital for Vicki to remain active in her community and daily life.

Remaining at home and in her community makes a world of a difference for Vicki. She can do things at her own rate, keep practicing her religion the way she wants, keep her pets, and her daughter is home in the evenings. In a nursing home, she would be without these liberties. Vicki refuses to go into a nursing home and will do everything in her power to remain independent, as she has witnessed firsthand the harm others have experienced.

If Vicki had all the care she needs, she could thrive in her community. If she had reliable transportation, she could be more active in the community—attend synagogue, see friends, go to the theater—instead she's stuck at home.

“I’m not participating in life,” Vicki fretted.

Vicki’s lack of care has affected her in innumerable ways. The State’s assessment tool, which calculates the number of weekly service hours she is approved for under the Choices program, fails to account for non-personal care services she qualifies for. This issue came up in both the PASSPORT and MyCare Ohio programs. As a result, Vicki has had to challenge the number of weekly hours she’s entitled to on multiple occasions because the hours were insufficient to meet all of her needs. She understands that many others are being denied access to vital services they are owed due to this flawed assessment mechanism.

Vicki fights for herself and others navigating the barriers and shortcomings of MyCare Ohio, and the PASSPORT program. She has filed complaints, reached out to news outlets, and written to the State, its legislators and even to Washington D.C. to demand that something be done about the mishandling of these programs. Vicki acknowledges her privilege in even knowing what her rights are and having a daughter who is an attorney who can help her.

"I'm frustrated, depressed, and anxious, as there seems to be no hope that the programs meant for the disabled will ever get the attention they need," confessed Vicki.

The barriers that Vicki continues to face are never-ending. Under the Choices program, Vicki has the right to choose the hourly wage for her care providers, and yet one of the managed care companies under the MyCare Ohio program denied her this choice. Additionally, under both the PASSPORT and MyCare waiver programs, Vicki was unable to have her dietary restrictions met by a company and received much disrespect and lack of compassion in response to her requests for any services that would be covered.

“These programs are meant to protect people who arguably need the most assistance, and yet it is this very type of program that has caused significant stress, anxiety, and hardship in my life for the last few years,” Vicki remarked on the waiver programs. As a result of the direct care crisis, the availability and quality of care providers has greatly decreased.

Vicki complains of aides who stole from her, neglected her, and were extremely unqualified to correctly care for her in the first place. Vicki speaks candidly about the workforce crisis: “Right now there are no aides available. People have found other jobs that pay more money, and they don’t want to be aides and not have benefits...my daughter went through the lists of people that they had as providers and we could not find one person.”

The most upsetting part of Vicki’s rightful concerns about MyCare Ohio’s and PASSPORT’s management due to her mistreatment, is that she has been penalized when she has voiced her concerns or objected to the administration. The managed care company Vicki was receiving assistance from terminated her Medicaid waiver services and deprived her of the ability to pay a qualified provider for almost two months because she indicated her intent to file complaints/grievances each time she experienced a perceived violation of law or policy. Exhausted, but not defeated Vicki asserted, “Fighting these complications has taken a heavy toll on me, but I want to see the light at the end of the tunnel and reach justice.”

When asked what changes need to be made to improve the direct care system, to Vicki, it’s essential that an education course is put into place for case managers who are going to be managing cases under the Choices program. The current case managers have not been taught the meaning of a consumer-directed waiver program—the care plan is centered around what the consumer wants and is not up to the managed care company to make the decisions.

Vicki proclaims, “I have a right to decide who my care team will be. Nobody seems to get that this is my life...not theirs!”

Ultimately, Vicki asks for her situation to not go unnoticed and for those in charge to address the problems within the current care system and workforce crisis. “I’d be fine if I got the help I was supposed to get...they need to listen to what I want, what I need,” declared Vicki.

everyone
deserves
care

*Ohio House, District 70, Representative Brian E. Lampton
Ohio Senate, District 10, Bob Hackett*

Cara and Corey

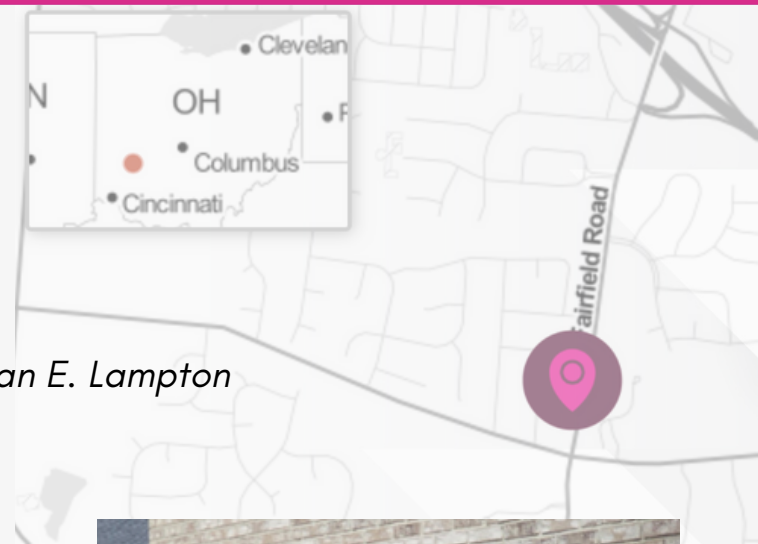
Cara became an advocate for disability rights because her oldest son Corey, 24, has Cerebral Palsy. While she is very active in her advocacy, her main role is providing Corey's daily care.

"He is very happy, he loves people, he loves to be active. He loves to be outside, he loves his dogs, his brothers – he likes to be with people," says Cara, describing Corey.

Corey leads an active life that includes activities such as horseback riding, skiing, Special Olympics bowling, baseball, kickball, and TOP Soccer. On road trips, he has travelled with his family to 46 states and 5 Canadian provinces. They often go hiking on their travels.

Corey was authorized skilled nursing services shortly after he was born, covered by Medicaid. He is non-verbal, in a wheelchair, and has limited communication. He has many diagnoses and medical requirements related to his extreme prematurity and Cerebral Palsy including a g-tube, ventricular shunt, seizure disorder, asthma, dysautonomia, and a neurogenic bladder requiring bladder irrigations and catheterizations. Because of Corey's conditions, he requires skilled care and close monitoring.

However, Cara reflects, "If I looked back over time, I would say we've never had the hours he has been authorized staffed."



Because of the difficulties Cara and Corey have faced in getting nursing shifts covered, she eventually turned to independent providers for a time. However, these posed their own challenges as there were many rule and rate changes. This led to difficulties for independent nurses that caused many of them to move to agencies.

Cara's struggles to maintain nursing for Corey continue today. Corey is authorized to receive 320+ hours of care a month, but right now he is only receiving an average 30 hours a week. Currently, they are working with two agencies and getting one nurse from each agency. Neither agency can provide them with backup if a nurse cannot work a shift. Due to COVID and other health-related issues, in the past seven weeks one of the nurses has only worked a single shift. The other nurse typically comes for eight hours, three days a week. The agencies are trying to hire with little to no success. Cara highlights the barriers agencies face when hiring because of the nature of direct care work, training requirements, and low wages.

Corey aged out of school right before COVID, which has made his care more difficult. While he was in school, he was able to be more active and was out of the house five days a week. Nurses at school were able to provide his medical care.

“Our story would be... he's aged out of school, and we are just not getting the support we need in the home and for him to go to day programs”

When school ended for Corey, Cara started looking into adult day services, and two were identified as appropriate after looking at fourteen providers. Corey attended a combination of two programs for 6 weeks before the providers were closed because of the spread of COVID. Only recently have the programs opened enough that Corey can attend two days a week, but Cara would ideally prefer that he go more than that. However, she believes going more than twice a week right now would be difficult, as he is often without a nurse to attend with him.

Corey is attending a new program as the two he previously attended do not have the capacity to take him back after COVID. Corey is being impacted not just by the shortage of nursing but that shortage of adult day program workers.

In the past, often months will go by where Cara and Corey received no help from direct care workers. Because Cara is a stay-at-home mom, she was told that she was not a priority, and nurses would often be pulled from Corey's care and given to families where one of the parents cannot stay at home. While Cara is understanding of this, it still poses a significant challenge.

At some points, she would stop trying to get help from additional agencies. "It was more trouble than it was worth for me to stop everything and try to train a new person again, than to just do it myself," says Cara. Especially if she spends days training someone and orienting them and then they don't end up working any shifts. The shortages of staff leave no nurses to orient new nurses to a case.

Cara acknowledges that she has help from her husband, but he works full-time and has previously travelled as a part of his job. Her other two sons also work and are not always available to help.

If Cara has to run errands or leave the house, she typically has to take Corey with her, and she would prefer it if he could instead be doing an activity that he enjoys.

Cara wishes that people understood the impact of having direct care workers coming and going on the people they are caring for as well as their families. She describes it as a strange experience to have someone constantly in your home that you don't know. She also highlights the impact on Corey's privacy and comfort as he receives his medical care from various nurses due to the high turnover rate.

Cara loves her son but describes her lifestyle as somewhat restricted. Given his age, she finds herself frustrated when people talk about needing time away from their kids.

Cara thinks to herself, “We’ve been away from Corey together four times in 24 years. There is just no help.”

And, in turn, Corey’s lifestyle is restricted when he does not have full access to activities in the community and limited social interactions when he does not have required staffing.

Recently, Cara has been certified as an Ohio Shared Living (OSL) provider. Because her son is over 18 and has an IO waiver, she gets paid a daily rate for his care. She also runs a small jewelry business. While Cara would have liked to be able to work more since Corey’s birth, she has been unable to as her daily life is fully consumed by Corey’s care. In addition to Corey’s hands-on direct care there is a lot of ancillary support Cara provides. This includes managing his health care (medication, supplies, appointments, and insurance) and his general care (laundry and equipment).

Currently, Cara can provide all of the care that Corey requires, including his medical needs. However, Cara is concerned for the future. When she gets older and is no longer able to care for Corey, she would ideally like him to be able to stay in their house with full time nursing. Corey has always led a very active life engaged in the community, and he would lose all of that if he was forced into an institution.

However, currently it’s hard to imagine a world where full-time nursing to support independent living is available.

“I look at what we get today and I think, how could that possibly ever happen?” She goes on to say, “There is a shortage, and it is impacting him, and it impacts us every day... in my opinion there has not been enough staffing from a private duty nursing standpoint as authorized his whole life.”

everyone deserves care

*Ohio House, District 70, Representative Brian Lampton
Ohio Senate, District 10, Senator Bob Hackett*

Maria's Story

In this Everyone Deserves Care story, we hear from Maria Matzik. Maria has not only utilized home and community based services her entire life - she's helped shape the way the programs work through legislative advocacy.

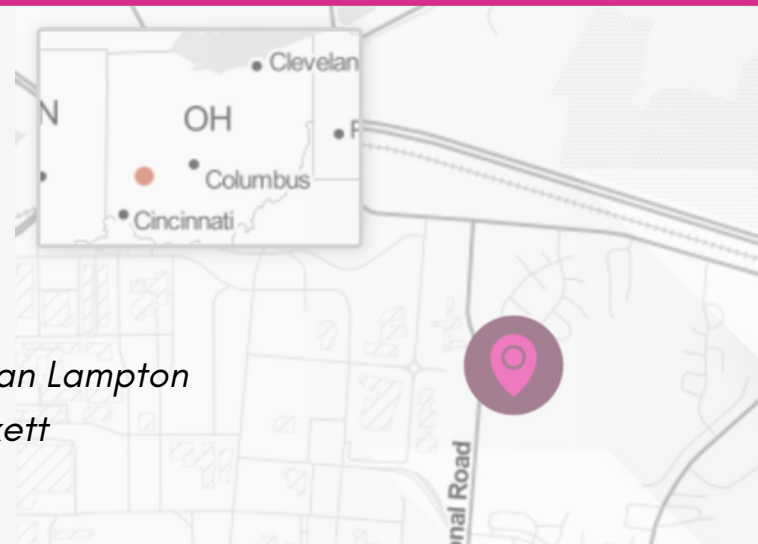
In this piece, Maria gives us a first-person look into the history of Medicaid funded waivers, with an emphasis on the importance of consumer-controlled care, and shares how these services are essential to living full lives.



Here is my Medicaid Story, in a nutshell:

My name is Maria Matzik, and I am a consumer of the Ohio Home Care Waiver program—a Medicaid funded program. I have Spinal Muscular Atrophy Type II; I use the assistance of a ventilator and I have a tracheostomy. For mobility, I use a reclining motorized wheelchair. I chose the option of Home and Community Based Services instead of the state's segregated, abusive, and expensive disposition to institutionalization.

I have used the Independent Provider Type since 1999. I was one of the few individuals who advocated for this option back in the mid-90s after going to Washington D.C. and speaking with many senators and representatives. My partner of 27 years and I worked on the rules for the Ohio Independent Provider program the entire time, from 1995 until implementation in 1998.



We also worked with many other states, CMS, and advocates to obtain the best program that Ohio would allow. It was a fight and definitely not everything that we hoped for, but it was a better option for most of us than home care agencies.

The Ohio Department of Medicaid (ODM) (at the time, called the Ohio Department of Health and Human Services) threatened us by saying that if we did not accept their proposed rules that we would not receive any program. Many of us were rightfully outraged. During the Ohio Joint Committee on Agency Rule Review (JCARR) hearings, the room was packed with standing room only. I testified in protest of their proposed rules and threats. I served them with a LARGE jar of Vaseline on top of a copy of their rules. This made enough of a statement to force the committee to reassess and come up with something that everyone could agree on.

We also advocated for and participated in, the process to write and pass the statute for the Ohio Medicaid Waiver Home Care Attendant Provider Type. I was the only individual who testified for this.

My journey into advocacy began on the day of my college graduation when Ohio's Job and Family Services threatened to throw me into a nursing home because the State did not offer the coverage I needed to "assure my health and safety".

I had just completed a 4-year degree at Wright State University in 1995; I managed to juggle a full class schedule, student attendants (who were phenomenal non-licensed individuals), and agency nurses. The agencies were my nightmare, but 90% of the nurses were incredible. I was looking forward to graduation and beginning a new life here in Ohio, as I am originally from Pennsylvania. However, Ohio decided that I was not safe since I did not have two hours a day covered, and the best place for me, if I remained in Ohio, was a nursing home.

One agency, so I thought, was my savior. This agency agreed to cover me and "eat" the two hours. I later found out that the real heroes were the nurses themselves.

The only reason the agency opted to “save me” was because two nurses working for me agreed to take a significant pay cut.

I have only used Independent Providers since 1999 and have had very little issues, by far less than in my years with home care agencies. Unfortunately, Independent Providers are becoming scarce and home care agencies will not cover my level of skilled needs. Most agencies will not even do shifts.

I have been my own advocate, as well as an advocate for individuals with disabilities across the nation, my entire life. If these programs were not in place, individuals with disabilities would be forced into institutions with no chance of ever leading a fulfilling life.

Though the old stereotypes still exist, I am here to tell you that people with disabilities can be productive citizens, taxpayers, parents, spouses, and even your employer given the options of appropriate services to achieve our maximum independence. In addition, I have a job, a wonderful partner, beautiful kitties, great friends, own an accessible home, own a wheelchair accessible vehicle, and pay taxes.

Medicaid Home and Community-Based Services (HCBS) waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities or intermediate care facilities for persons with mental retardation. The HCBS waiver program recognizes that many individuals at risk of being placed in these facilities can be cared for in their homes and communities, preserving their independence and ties to family and friends at a cost no higher than that of institutional care.

I am writing this to not only share my story, but to inform you about a population that is almost always overlooked: individuals with disabilities aged 21 to 64. In most cases, these individuals do not have any family or spousal support. I am a part of this population and I diligently fight to ensure we all have equal opportunity to live a full and productive life. This is the population who desperately needs Medicaid and Medicaid Waiver services.

Many years ago, a large group of consumers, parents, and advocates began a long battle with the state of Ohio to create a home care program that not only provided the services that an individual needed to remain in the community, but one that offered consumer choice—the most important aspect being consumer control. We have come a long way in the past two decades and gained many positive changes that should be recognized, but we have also faced some recent setbacks and have far to go to achieve the “choice” and “control” we advocated for over 20 years ago.

When we started this advocacy effort the progress was slow and frustrating because the Bureaucrats could not grasp what it was that we were asking for. It was next to impossible to engage in any form of dialogue even though we were the population who would be impacted the most by their decisions. We were lucky if they even took the time to return one of our phone calls. The sense was very clear that they believed that they knew what was best for us and did not feel the need to include us in creating this new program. Finally, a statewide effort was made to involve representatives from our regional The Health Care Finance Administration (HCFA office), which is now Centers for Medicare and Medicaid Services (CMS). The tide began to turn when the requests that we had made for things like “choice” and “control” were validated by HCFA. Focus groups were created and plans were set into motion. Then, time moves on and Waivers are born.

Many years passed and once the Medicaid-funded Waivers were put into place, there were not many dealings with the Bureau. Then, a new administration brought changes to the budget and proposed changes to the disability population once again. We made attempts to speak with our legislators (just as we do today) to no avail.

Most people view disability as an “illness” or a “condition.” But the reality is that it is just a natural part of life for most of us.

I don't have to think about what my needs are because I know my needs just as you know yours.

The difference is that you perform your own tasks and I cannot. I must think about who will perform my tasks and how. I have always trained all my providers, both licensed and non-licensed. I have trained all my providers to do everything from moving me correctly to changing my tracheostomy. I have been hospitalized once in 1993 for respiratory failure caused by inappropriate ventilator settings by my doctor.

For many years, because of the nursing shortage, I have not been able to find enough nursing coverage. That means that when I got up in my wheelchair on Friday morning I do not go back to bed again until Sunday night. That means that I can only get washed up, but not take a complete bath. That means that I stay in the same clothes. That means that I do not have tracheostomy care to clean my trach. That means that I remain on my left side because I cannot roll in my wheelchair. That means that if I need to go to work on the weekend I still go. That means that I get little to no sleep. Ask yourself, "Can I do this?" Most of you will answer "no."

I have had the choice, I either go through what I have just described or go to bed on Friday night and still not be able to do several things mentioned above, like trach care, not be able to go anywhere, do anything and get depressed because I am not taking part in life. For me, this is a choice that I am willing to make because it is a "choice." If we lose our Medicaid coverage or continue to have issues with hiring reliable and responsible home care providers we will have no choice! We will have no life!

People with disabilities are resilient individuals with a passion for life and a drive to succeed.

Most non-disabled individuals will never, and could never, endure the oppression, segregation, discrimination, humiliation, ignorance and pain that individuals with disabilities face throughout their entire lives. We are constantly having to prove our worth and value to a society that only values wealth, beauty and success.

It is time that society, and even some of our best intended advocates, stop trying to paint a picture by using our inabilities and our financial drain on society and the budget. It is time to fight like our life is in danger because it is!

Remember: The Disability Culture is the only culture that anyone can enter at any time.



Ohio House, District 1, Representative Dontavius Jarrells
Ohio Senate, District 15, Senator Hearcel Craig

Allie's Story

Domestic Violence Survivors with disabilities face enormous hurdles to access care. While I believe Everyone Deserves Care, this is not happening in Ohio. People like me have faced vigorous challenges, more than the average person, in this care crisis.

I am 36 years old. I have congenital heart defects, a chromosome disorder, and several other disabilities. My main condition is called Mast Cell Activation Syndrome.

My day to day life consists of breathing treatments, very strict protocols for medication administration, suctioning, logging any kind of intake, side effects and vitals, and utilizing specialized compression equipment. I need high levels of supervision for any kind of activity that involves food intake. I need constant reminders to drink water because any bit of dehydration can lead to an emergency room visit. I am also in a wheelchair and utilize extensive help with my activities of daily living. My care is very important to my overall functional levels.

The direct support crisis challenged my ability to cope with life these last few years. Ohio has many systemic challenges to why people are unable to access care. Low wages, managed care contracting issues, payment of providers and lack of accessibility in waiver services.

I was on a backup plan for almost 300 days because my managed care plan refused to problem solve provider billing issues. One provider went 471 days without pay. Two others providers never received payment for services rendered.

I faced discriminatory and unjust barriers to accessing care. I was repeatedly bullied by my managed care plan about protocols in place to keep me safe from abuse.

The ability to access services and supports should not have so much red tape attached to it that it forces someone in a vulnerable position to lose hope or to be forced to be in vulnerable situations that subject them to abuse or harm because they need care.

This is my story... the state of Ohio failed me when they allowed a managed care entity to purposely block access to a qualified Medicaid independent provider violating Appendix K emergency rules. I waited 17 months to contract a home care provider. I was bullied about a nursing home, spoken to in dehumanizing tones, and even with ombudsman advocating for over a year I went without many of my basic needs met. I faced some of the most unjust discrimination to access care.

I didn't stay silent... I painted to survive. I also dealt with the unjust challenges of being subjected to more abuse and violence. Advocacy, art and peer support helped me have my voice to hang on despite all that was going on around me. I spent a lot of time in out of the emergency room, infusion center and even inpatient in the hospital. I know that it cost state more money – if they would have done the right thing, they could've avoided those things.

#EveryoneDeservesCare, yet I kept losing care due to billing and pay problems that went unresolved too long. The low and delayed pay makes it so people cannot recruit workers and keep them long term.

I had to relocate because it was obvious I could not access the care or services needed under my managed care plan. They had broken me to the point, I was in an extreme mental health crisis and in a vulnerable place that jeopardized everything I worked so hard to free myself from.

I switched managed care plans and there has not been much change. I have some care. It legit is rocky every day. There is no stability when my provider is on verge of homelessness due to low wages. I continue to make art, use my voice in advocacy, and stay connected to peer support groups with other people with disabilities.

Change is necessary! This is most severe crisis ever! We need everyone to speak up! Reality is #EveryoneDeservesCare.

everyone deserves care



Ohio House, District 1, Representative Dontavius Jarrells
Ohio Senate, District 15, Senator Hearcel Craig

Jynette's Story

I am 63 years old and live in Columbus, Ohio, with my son who had to move in with me so that I would have some consistent care.

I am actively involved in my community, and have provided Christmas for families with children for 26 years. I am the creator of 614 Youth Prevention Agency, and put programs together for middle and high school-aged students, especially focused on the holidays with our toy giveaways. I also volunteer at multiple different agencies at a time.



My issues with gaining adequate care started as early as 1995. I worked at first as a medical secretary at OSU and fought for years to receive my Social Security (SSA) benefits—which I didn't start receiving, even though I was in pain, until 2011. Because of my lack of transportation, which has been a problem since 2018, I lost a position with Nationwide Children's hospital. Some days, my ride would be cancelled or dropped. Then, my bus pass expired, and I was waiting for a month to get a new one mailed back to me.

I am enrolled in a Medicaid-funded waiver program and should be receiving 12 to 14 hours a week of care for my needs, which often go unnoticed.

My lack of home aides really became a problem for me in 2015, following a stroke that left me unable to attend to my home the way I want to. I rely on services to take out my trash, clean dishes, and organize things around my home for two hours every day. Right now, I am receiving no hours due to lack of consistent aides. I also rely on services for things like my Stairmaster and other equipment that helps me physically, as I'm unable to stand or walk around for long periods of time. Due to my physical needs, I also don't drive – so I rely on services for transportation.

In 2015 and in 2018 my whole world changed. A landlord did not follow Section 8, so I had to pack up all of my stuff and move into a nursing home in 2015 for three months. That was such a stressful situation. When I go through an anxious situation and I can't control it, my whole-body panics, and my stomach starts acting flippy floppy.

That time in the nursing home was rough, and I constantly had to advocate for myself and others every day. The atmosphere was not good. My roommate was on the floor every time I woke up in the morning. Her health aide would often be sitting outside of our room and not checking on her, and I would have to go get help. Living there is why I have such bad problems with my legs even today. My thyroids around my body went out of control. They had to remove the thyroids and they took my voice away, and I had to do physical therapy.

When I was able to transition out of the nursing home I did so as soon as possible. I applied for a program which gave me this application to get movers, packers, paid for my deposit, electric, and gas. Two weeks later I moved into a house. I prefer to live in my community, but without consistent care it's hard to maintain my life.

So, now I am at my wits end with all of this, and I don't know what to do. I don't receive the care I need, or the help to be able to figure it all out.

Over the years this has caused severe underfunding and it's hard for me to keep my lights on.

Between systemic barriers and this lack of care, navigating it all is exhausting and stressful, and I am consistently struggling to keep my head above water to look for higher paying jobs. It's overwhelming.

Unfortunately, my family, and friends can't provide support to me, because they also have full-time jobs and lives. Because of my health issues it's hard to work a full-time job. I can only find positions like 504, or jobs like AARP, AmeriCorps VISTA, or others – that way I will not lose my benefits.

I feel like isolating myself all the time because I get sick of fighting. I am always in pain, my knees hurt so bad all of the time, and I can't walk or stand up. I can't move out of my place or make a better life, because my income keeps going up and down. My neighborhood is unsafe – with gun shots almost every night. I am so done with all of this, and it's hard to find faith.

All I want to do is to live a productive life and help others. I want to promote good deeds. Like the 614 Youth Prevention Agency's time helping give hot meals to Latitude 425 – the folks that got put out of their houses. Our agency was able to give them a hot meal for the whole month of January. We are now calling this the "Elements of Life" our plan is to people's need at their home so we can get them food and special needs. I want to have the care I need to be able to do more things like that. I want to focus on the things that matter and have the energy to do what I love – which is empowering our community with resources. Especially our homeless people and our youth.

When I'm fighting for care, I cannot live the life of service as well as I want to. When you can't help yourself, it's hard to be able to help others. Money is not enough, and you can't survive without care – especially now. It makes me sick to my stomach. I just want to see change. I feel like I have no control over my life. They do.

everyone
deserves
care

Ohio House, District 23, Representative Daniel Troy
Ohio Senate, District 16, Jerry Cirino

Kevin and Carolyn

"This Is Us"

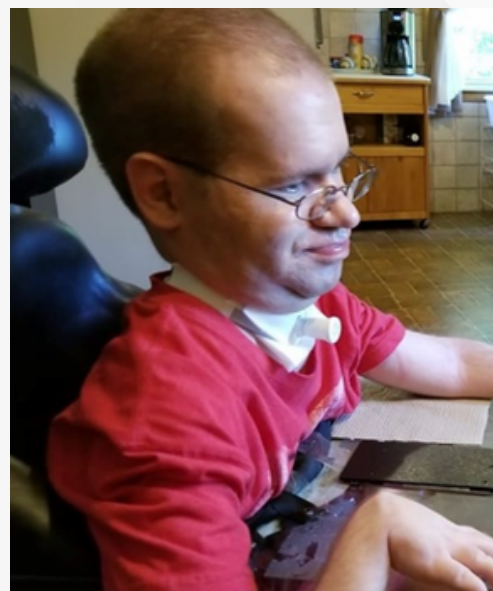
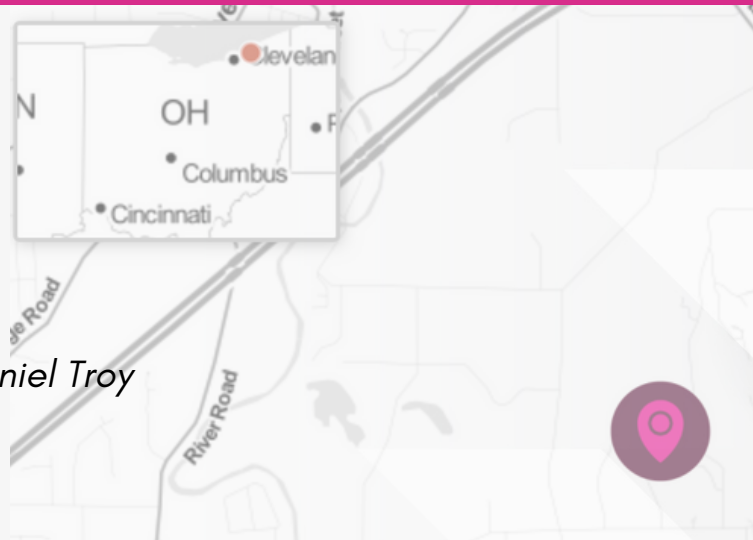
The Role of Direct Care In My Life

I was born on June 24, 1983, a fairly big, healthy baby. By six to nine months I had stopped rolling over and pushing myself off the bed. At one years of age, I was diagnosed with spinal muscular atrophy, the number one genetic killer of children under the age of two. This is a neuro-muscular disease that affects the motor neurons in the spinal cord causing them to weaken and die off.

Obviously, I made it past the age of two. I actually did okay until age three when I had my first respiratory infection. Age eight saw the introduction of a tracheostomy tube, ventilator (for sleeping and illness), and g-tube (gastronomy button). The g-button has been used as a supplement to my mechanical soft diet and for medications. It was then that I started receiving nurses through Medicaid-funded homecare.

My disease has progressed as I have gotten older. In addition to the ventilator, I have several more medical machines:

- IPV (Intrapulmonary Percussive Ventilator) machine – two treatments/day. This helps to mobilize my secretions
- Chest Wrap – two treatments/day – helps to break up my secretions



- Cough Assist Machine – PRN. Almost every day – helps to bring up my secretions
- Trobramycin aerosols – two weeks on/two weeks off – helps to control pseudomonas (bacteria) in my trach.
- I also use a feeding pump for nutrition via the g-button at nights.

I have been allotted 115 nursing hours per week. I can count 56 as regular (which includes 47 night hours so my mother can sleep at night). Because of my extreme weakness, I have to be turned every 1.5 hours to prevent bedsores, sometimes suctioned down my trach and hooked up and disconnected from a feeding pump at night. Without a nurse, my mother puts some cushions on the floor to try to get some sleep.

My mornings include 4-4.5 hours of respiratory treatments, personal care and breakfast. This takes us until about 12:30. I am free until about 3:30, where I have water/juice and put back in bed for a change of position and void. Then again, we start the whole process over at 8:30 p.m.

Life without Adequate Direct Care Services: The Impact

Kevin writes: As you can see, my 39 years have been challenging, but none of it prepared me for the last two years. Yes, the COVID-19 pandemic, and the isolation it necessitated, was bad enough. It is all the more stressful without sufficient nursing.

The anxiety this causes can feel paralyzing at times, especially since there is no end resolution in sight. How can my mother and I possibly plan for the future when getting through the day is tough enough? The nurses just are not there. This **MUST** change.

Pay for homecare nurses and aids needs to be increased, and benefits need to keep up with the modern workforce. I do not know what else needs to happen, but clearly, more needs to be done.

I have needed homecare nursing for 30 years. The current shortage is, by far, the most dire and devastating in my memory.

Families – like ours – are desperate. We will persevere as best we can, but we need help. Please help us.

Carolyn, Kevin's mother, writes: On June 24, 1983, we welcomed our second son into the world. All seemed right until he was diagnosed with spinal muscular atrophy (SMA) at the age of one. Our lives would forever change.

We were told he might not live past the age of two. He did and we thanked God.

We were told there might come a time he might need to get a tracheotomy and go on a ventilator. He did and we were slower to thank God.

We were told he would be eligible for nursing through a Medicaid-funded Ohio Waiver Program. He was and once again we thanked God.

We were told people with SMA are, for whatever reason, usually quite smart. He was and we thanked God. He was intelligent, but it was the nurses that accompanied him to school that made his education a truly rewarding experience. Not only Kevin benefitted, but every student/teacher he came in contact with experienced the benefits of inclusion/diversity. He went on to receive a B.A. in communications (summa cum laude) from Lake Erie College. In fact, it was his nurse that accompanied him on stage to receive his diploma.

We weren't told how much his medical condition would progress. Technology has come a long way. We should know. Kevin has almost every respiratory machine there is. Still we thanked God for the advanced technology that allowed him to stay with us.

We weren't told that there would come a time when the nurses pool would dry up thanks to the pandemic. But, it has and I ask, what's up God?

At age 71, I never expected my life to be this hard. And yet it is. Kevin's care calls for nighttime nurses so I can sleep, along with daytime hours to handle his very involved care. Without them Kevin and I have become prisoners in our own home. The lack of nurses has not only affected Kevin's physical care but also his emotional and mental well-being. I have had to postpone needed doctor's appointments and procedures. At my age, that's probably not the best thing to do. We have had to discuss Kevin going into a hospital if I suddenly get sick or need surgery because of the lack of nursing care. Can't you help us God?

And then I got to thinking. Perhaps God helps those who help themselves. Perhaps our role is not just as parents, but also as teachers and advocates. I still believe that most people are good and would want to help if they could put themselves in our places, if for only a day.

So, I appeal to all these good people – legislators and Medicaid personnel to do the right thing. Establish a committee to investigate how to recruit and keep both aides and nurses long term. No doubt increase in pay will be a key component, but also ways to recruit nationally and thinking outside the box when it comes to regulations.

Please open their eyes and ears God.

everyone deserves care

Ohio House, District 8, Representative Beth Liston
Ohio Senate, District 16, Stephanie Kunze

Christine's Story

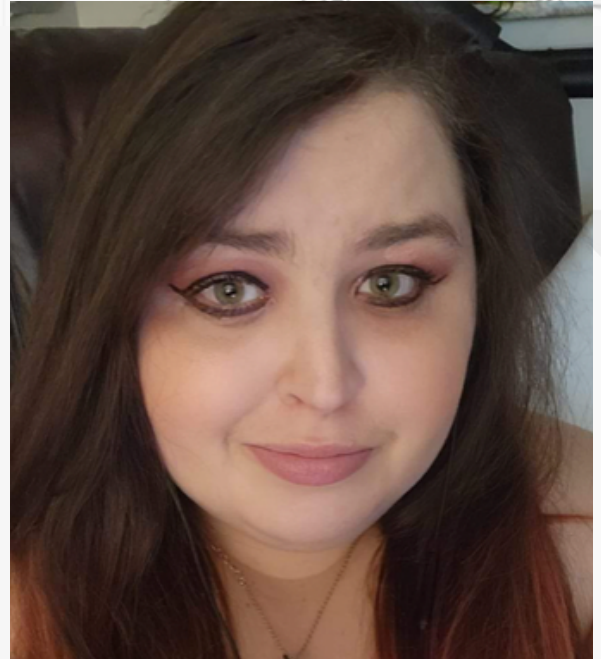
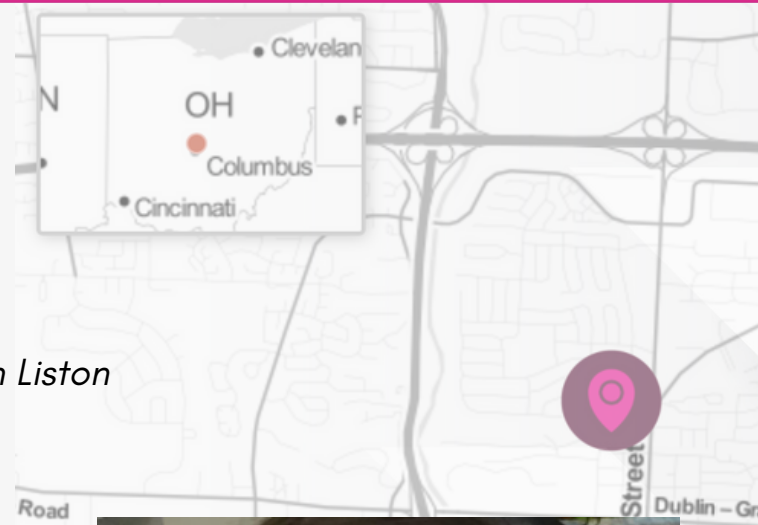
Christine has family, friends, a boyfriend she met through playing Pokémon Go, and a cat named Riley. She also has several hobbies and interests.

“I’m a writer, I love to write. I’m an artist, I draw, I paint,” says Christine. Her bedroom walls are decorated with her artwork.

Christine is diagnosed with Borderline Personality Disorder, Bipolar I, Panic Disorder, Anxiety, and Depression. She also has physical disabilities that affect her mobility.

She was authorized for approximately 20 hours a week of direct care services through a Medicaid-funded waiver a couple of years ago. In the beginning, she shares that it was easier for her to find aides, and she liked the aides that worked with her. However, starting at the end of 2021, Christine could not even find an aide to cover the nine hours needed to meet her minimum needs. Currently, she has not had an aide since March 2022.

“Basically, my mom has been my aide... and it’s really hard on her because she is in her sixties. It is not easy for her to do this stuff and she basically has to do it all by herself,” notes Christine.



Christine has also had issues with aides previously, commenting that past aides have been rude to her or even stolen from her. “It’s really hard to trust someone that you don’t know to come into your house,” says Christine. The high turnover of direct care workers makes it hard for Christine to get comfortable with the people providing her care.

Her situation was particularly difficult after she had surgery in March. Before the procedure, Christine had an aide that an agency provided. However, after Christine’s surgery, the aide left the position to take a higher-paying job. The agency told Christine they would try to find her a new aide, but eventually told her that they were unable to help her.

This left Christine in a difficult position, as she was fresh out of surgery and had no support. The recovery process was extremely painful. Christine had trouble walking and was unable to bend over or lift objects over ten pounds. She reports that she mostly just stayed in bed and slept, because she did not have an aide to help her.

“I just had to bite the bullet – I had to go through the excruciating pain to make myself meals and make sure my cat was taken care of – I couldn’t even empty her litterbox.”

Even as she is healing from her surgery, Christine notes that she does not need an aide just for her physical condition. “With my mental health, it is very hard for me to organize my thoughts and cope with all of this... running a household is very overwhelming for me.”

Christine is especially concerned about her living situation because she lives in subsidized housing where apartment inspections are frequent. She has been reported several times for unclean living conditions and was almost evicted. She says having an aide would help relieve the constant fear of being kicked out of her housing.

“I try to keep up on the chores as best I can, depending on how I feel during the day, but it’s just so hard.”

Christine is emphatically against living in a nursing home or group home environment, saying that she would only consider it as a last resort. She has heard of negative experiences in those types of living environments, experiences that she would rather avoid. Additionally, Christine values her independence.

“I prefer to live on my own – I like making my own rules.”

Christine needs an aide to help her with daily tasks that currently take up too much of her time. It is hard, both physically and mentally, for Christine to maintain these tasks without help. She wishes there was a system that provided back-ups or last-minute support to those unable to find aides.

Recently, Christine was assigned a new aide by the agency. However, she is not optimistic that it will work out.

“It’s probably going to fall through like the rest of them have,” she states.

After experiencing many aides come and go, often leaving for higher paying jobs, it’s hard for Christine to imagine a stable future where her right to care is consistently met.



*Ohio House, District 8, Representative Beth Liston
Ohio Senate, District 16, Senator Stephanie Kunze*

Julie's Story

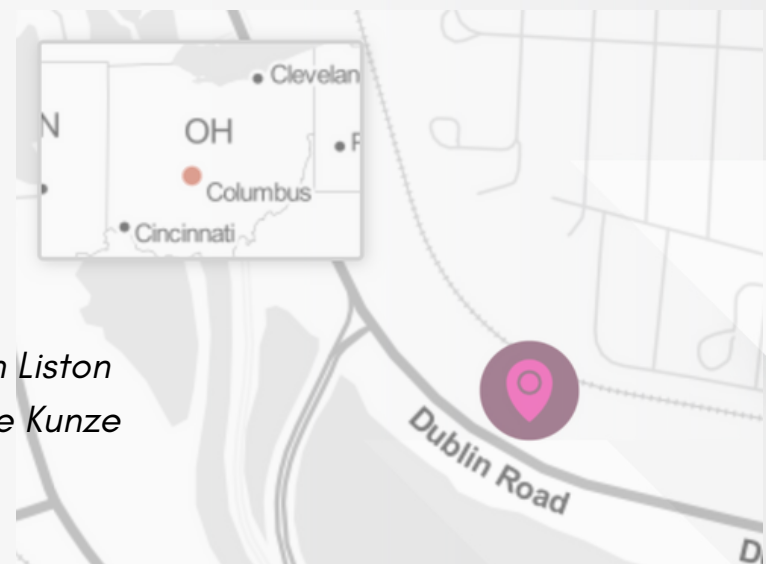
Julie McComas has been providing services for people with disabilities for three decades.

“I got my start working with people with disabilities directly when I was in college,” she shares. During this time, she worked in a group home and with a group for teen moms with disabilities.

After these early experiences, Julie continued her career in the field of disability services. She has worked for the Bureau of Disability Determination and the Bureau of Vocational Rehabilitation, both of which are now a part of Opportunities for Ohioans with Disabilities (OOD). She has also worked independently as a consultant for the Ohio Department of Developmental Disabilities (DODD). Currently, she consults for Griffin Hammis Associates, an international group focusing on employment services for people with disabilities.

Julie started providing services through her own company, Altitude Initiative, in 2014. Originally, its primary focus was providing employment services for people with disabilities. However, Julie eventually expanded the outreach of her organization to include more 1:1 community focus support. She also added a non-medical transportation service.

Julie states that part of the reason she started Altitude Initiative was because of the people with disabilities she worked with as a state employee.



“We were just constantly hearing from people about how they just wanted access to the community; they just wanted to be a part of the community.” She explains that many of the people she worked with wanted to find employment and live more independently.

Julie’s mission in starting Altitude Initiative was to provide services tailored to each individual with a disability to help them achieve their goals. She wanted to help people answer the question: “What do you want and where do you want to fit in?”

Julie describes the work she does as rewarding. She values the relationships that she and her staff built with the people they served. She also enjoyed witnessing the impact her company had on the lives of people with disabilities.

“Seeing people have a goal and reaching it with the support they want and the support they need has been awesome.”

However, unfortunately Julie had to close Altitude Initiative in June 2022. She notes that the main issue was the shortage of direct care workers, which was compounded by the Covid-19 pandemic. Julie tried to maintain a supportive environment for employees but cites the lack of funding as a major issue.

“It’s been very difficult to hire people and to be able to pay them what they want to be paid now, and what they should be paid now.”

Julie tried to launch hiring initiatives, but these were not enough to rectify the issue. She remembers one time where she hired ten individuals, and only two reported to work.

“I’m filling in the gaps. As the owner, I wasn’t going to let the people we serve not get what they needed.”

However, Julie's gap-filling resulted in her working 16-hour days almost every day for the last two years. She shares that this grueling work schedule has resulted in her facing long-term physical health issues. Eventually, Julie realized that the company was unsustainable. She sent out a 90-day notice to her clients that Altitude Initiative would be closing.

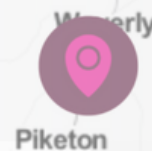
Julie wishes that people understood that direct care service workers are skilled workers. They need to be equipped to handle crisis situations and administer medication. They also need the unique ability to foster community and build relationships.

"We're asking them to be superhuman," states Julie. "We put a lot of trust in them, and we ask them to do a lot, and we hold them very accountable for their mistakes, and yet we just don't pay them for that kind of work."

Julie believes that the issue of wages is particularly difficult as so many direct care workers are single women with children. "I think that many direct support workers get into this field because of a passion for service," reflects Julie. "But passion doesn't pay the bills."

After the closing of Altitude Initiative, Julie is spending more time with her family. However, she continues her work as a consultant. She also volunteers her time to some of the people who previously received services through Altitude Initiative, helping with daily tasks such as transportation and grocery shopping.

"I love these people," shares Julie. "The staffing crisis didn't stop, it's worse now that we're not in service."



*Ohio House, District 91, Representative Bob Peterson
Ohio Senate, District 17, Senator Shane Wilkin*

JW's Story

JW describes herself as a normal 35-year-old. She lives with her beloved rescue cat, Callie, and hopes to own her own home someday. “I’m very much like every other adult. I just need a bit of help.” JW is a wheelchair user and has a trach. She qualifies for 12 hours of nursing care and 5 hours of home health aide services every day through the Ohio waiver program. However, JW hasn’t consistently received all the care she qualifies for since 2010.

Her home health aide typically provides between 1 and 3 hours each evening. JW relies on this aide to help her go to the bathroom, eat dinner, and get to bed. While the home health aide provides many critical services for JW, they also play an important role in keeping her company.

JW’s home health agency frequently rotates aides to different homes, which prevents her from building trusting relationships with her aides. A few years ago, JW had an aide steal a significant amount of money from her home, further stressing her ability to build relationships with her aides.

One of the highlights of JW’s care is her nurse. She has been working with JW for 30 years – since she was only 5 years old. But JW cannot rely on her forever, as she will be retiring next May. JW relies heavily on her nurses, especially to maintain her trach. She is afraid of what will happen if she cannot replace her. “If I don’t find more help, I’m going to have to go to a nursing home at the age of 36. I don’t want to do that, mainly because of my health.”

JW fears the widespread diseases that claw their way through the vulnerable inhabitants of nursing homes. She also fears having to give up her cat, who likely cannot go with her to a nursing home. As a counselor, JW has worked with clients in nursing homes. She reflected upon a time she was visiting with a client who had pushed the call button for assistance to use the bathroom. An excessive amount of time passed, and the woman ended up soiling herself while waiting for staff assistance. Moving into a nursing home at the age of 36 would be extremely detrimental to JW's wellbeing. She is considering moving into the home of a friend, "but then she would be the one 'stuck' taking care of me."

JW knows that change in the direct care workforce will not come over night, but she recognizes some simple solutions to help recruit and retain quality home health aides. It starts by breaking down some of the stigmas about the job. People often show up to care for JW and are shocked that she is not an elderly woman.

"I wish people know that young people need help too sometimes." She also explained that a lack of knowledge about what the job entails can prevent people from entering the workforce. For example, many people falsely believe that if they are an aide for a client in a wheelchair, that they will be required to pick them up frequently. However, many clients have power lifts. JW recognizes that the misconceptions go both ways. "I wish people would appreciate home health workers more... because this is a tough job." The most vital need is an increase in pay. One of her aides, whom she really likes, is considering quitting because he isn't paid enough to support his two children. "I have to constantly worry about that."

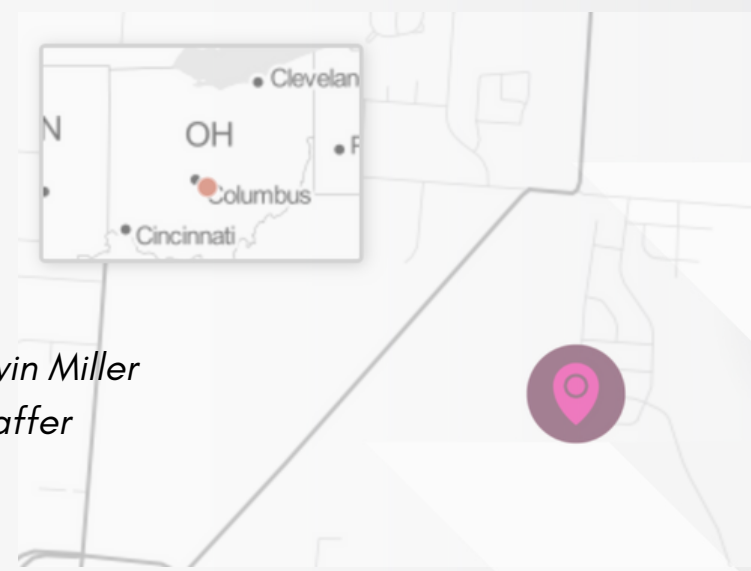
In order to recruit and retain more quality home health aides, JW believes there must be a change in systemic policies. "They (home health aides) need benefits... vacations, sick days, and mental health support." These types of changes need to come from the top down.

"My number one wish is that lawmakers... would know what it's like."

“When I was a kid, my parents always told me that people who are in charge of this aren’t affected by disability, so they don’t know what it’s like to have to worry about that stuff. I wish they knew what it was like.”

Finally, JW hopes to see support expanded for the families of people with disabilities. “My parents constantly worry about me and what’s going to happen when they die. I would love to see more resources for parents, guardians, and other family members.”

Without intentional change, JW and others like her will continue to lose their freedom, including their ability to live independent and productive lives. JW wants to live like every other adult. “I enjoy doing what every other 35-year-old does. I just need a bit of help.”



*Ohio House, District 69, Representative Kevin Miller
Ohio Senate, District 20, Senator Tim Schaffer*

Luke and Heather

For Luke, a 7-year-old boy with autism, direct care workers can help him work on social and behavioral skills, take him on outings in the community, and assist him with personal care needs like eating, bathing, dressing, and toileting.

Luke has two loving parents who are able to provide the majority of his care, but both his parents need to work to support their family, and because Luke needs 24/7 attention, additional support from direct care workers is crucial to his safety, well-being, growth, and happiness.

Heather, Luke's mom, shares that the process of getting Luke the care he needs has been strenuous and is an ongoing fight.

Originally, Luke was only allocated 5 hours of care per week. While any support is helpful, finding an agency that was willing to send an aide out for such limited hours was impossible. The low pay, difficult process of getting a case set up, and the high-skill level of work required to provide his care, meant that a case that can only supply 5 hours a week simply wasn't worth it to many provider agencies – especially with the added system pressure of the shortage of workers.

Even if Luke was able to get his 5 hours of care consistently covered, Heather feels it wouldn't be enough. Heather's relentless advocacy has increased Luke's care to 10 hours per week, but she feels frustrated that the officials who are determining what Luke needs are not the people that know him best.

“The people that are making these decisions, they’re not living in our shoes every day,” she says. “Right now I’m doing the evening shift at work. Before I go to work, I drop Luke off at my husband’s office. So he’s spending 4 hours in an office while my husband’s trying to work. He is getting into the trashcan and having meltdowns, so it’s causing stress for both of them. Luke doesn’t need to be in an office. He needs to be going to the park like a little boy should.”

Heather shares that Luke loves to be outside.

“He’s just as happy playing with sticks and stones than any toy,” she says, laughing. “He also loves horses and playing in water. And he’s a master at puzzles, and he can work a tablet or phone like no other. It’s amazing.”

One common – and harmful – misconception Heather has faced is the idea that Homemaker/Personal Care (HPC) services are just “free babysitting” for parents.

“I’d like to see someone find me a babysitter that’s qualified to care for Luke,” Heather challenges.

Heather feels that the idea that direct care workers are just babysitters is insulting both to the families and people that need this care and to the skilled workers who provide it.

Having the support to get Luke out into the community is something Heather is particularly adamant about. For kids with autism, early exposure to new experiences and lots of practice is essential to helping them build strong foundations. While she and her husband do take him on outings, they both work full time, have other children to care for, household chores to manage, and so they just aren’t able to dedicate as much time to these experiences as Luke needs.

“Just like any other kid, Luke can feel when there is stress or tension at home,” Heather says, “if we had help [from direct care workers], it would lessen that stress and Luke would only benefit.”

Heather’s advocacy for Luke – from pushing for him to receive services, to searching for direct care workers, to ensuring he receives support in school – is hours and hours of work on top of her job as a nurse and as a mother to three kids.

“It’s like learning a foreign language,” Heather says of navigating the complex service systems. “It’s intimidating, but we love him to death and just want what’s best for him.”

everyone
deserves
care

*Ohio House, District 73, Representative Jeff LaRe
Ohio Senate, District 20, Senator Tim Schaffer*

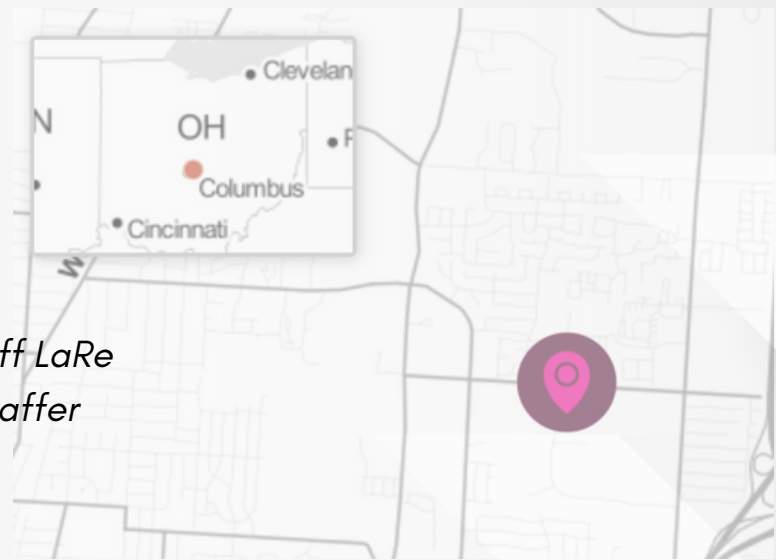
Robert's Story

Born and raised in Ohio, Robert J. Doersam's life has been guided by his dedication to learning and his passion for being an active member in the community.

Growing up in the 1950s and '60s, well before the passage of the Americans with Disabilities Act, Robert had to navigate many barriers as a person with Spinal Muscular Atrophy Type 3 in order to get an education, including having to travel to a neighboring city to attend high school in a more accessible building. For Robert, the hardest part of college wasn't difficult classes or the heavy workload, but inaccessible classrooms. Still, Robert graduated in 1976 with a bachelor of arts in political science from Ohio Dominican and later completed social studies teaching certification at The Ohio State University.

Robert's first career was in the Franklin County Prosecutors Office. He'd dreamed of teaching history and eventually getting a law degree, but encountered too many accessibility barriers. Instead he went on to serve the state for over 20 years, first employing his analytic and communication skills as a training officer, and later by working in the IT department of the Ohio Office of Budget and Management.

In order to learn, live, and work in the community, Robert relies on direct care workers to help him with daily living tasks like showering, getting dressed, eating, etc. In order to get to his job in downtown Columbus at 8 a.m., Robert would wake up at 4 or 4:30 a.m.



“Those were the good old days,” Robert says of his time working in offices. “Getting ready took a long time, but I was willing to make the investment to get to work downtown every day.”

In the early 2000s, Robert was struggling to hire and retain enough qualified care workers. Additionally, he began to experience difficulty operating his van’s steering system, which led to safety concerns in his ability to get to work. He asked his supervisor if he could work part time from home, but was denied, and instead ended up having to retire early in 2006.

As someone who truly enjoyed working – Robert describes the two joys of his life as “family and work” – the decision to retire was not easy.

“I like to think that in a better world, not a perfect world, in a better world, I could get enough care to take care of my medical needs and still be able to work at least part time, if nothing else, from home.”

Nearly 16 years later, Robert is still navigating problems with getting enough care – and they’ve only gotten worse, exacerbated, in part, by the COVID-19 pandemic. In 2020, his lack of care forced him out of his home and into a nursing home, but due to his individualized needs, the environment of a large care facility was dangerous for him.

“I was just left lay in bed until noon-ish, and I was missing meals. I had injuries to my joints because staff did not listen to my needs,” Robert shares. “The treatment you get in those facilities is not humane. People are just basically put in bed and left to rot. I know some facilities do better than others, and the one I was in was not the worst by any stretch, but it was still not able to care for me appropriately. There is a whole booklet on standard of care for people with my disability, and [the nursing home] didn’t even come close to it.”

“I ended up leaving because I was lucky enough to have family who said, ‘Obviously, [the nursing home] can’t provide your care.’”

These days, Robert is back in his home. He has three caregivers who cover daytime shifts while his wife is at work, and one who can cover some night hours. However, he's not getting nearly enough care and new workers are impossible to find.

While his wife is able bodied and helps provide some care, as she gets older the tasks Robert needs help with become more difficult and dangerous for her.

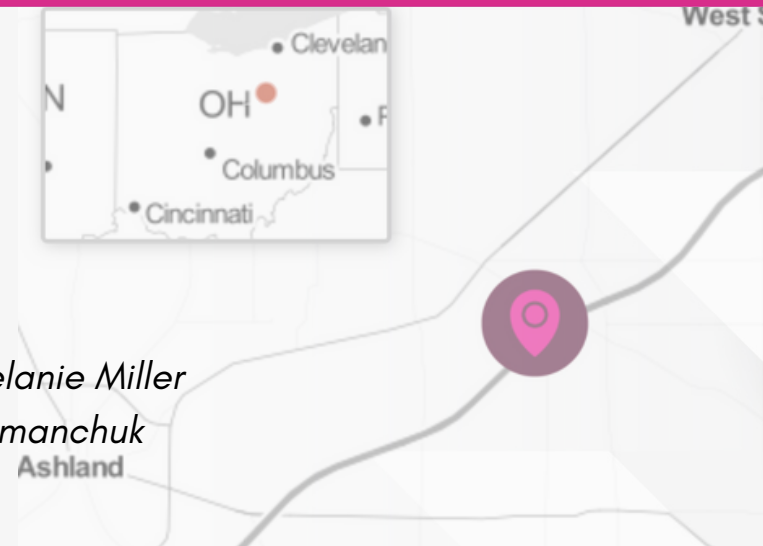
In addition to leaving work early, Robert has also lost the ability to attend church, something his family did weekly, because it's just too difficult without caregivers.

"[Not having enough direct care workers] is obviously very limiting" Robert says. "I think if it wasn't for my wife and my son, I would rather exit this life."

Then, of course, there's the obvious health and safety risks that come with a lack of care. Yet, while this crisis persists, having profound impacts on Ohioans, little action seems to be taken by those in charge.

"Policymakers want to turn their heads the other way and pretend the problem doesn't exist," Robert says. "I'm here to tell you it's very real, very real."

everyone
deserves
care



Ohio House, District 67, Representative Melanie Miller

Ohio Senate, District 22, Senator Mark Romanchuk

LC's Story

When LC's daughter was born, doctors told LC that they did not believe her daughter would live.

That was 26 years ago. Now LC describes her daughter as a happy young lady. LC and her family have found a way to live in their community, despite many societal barriers. However, that doesn't mean the journey has been easy. LC has been fighting for adequate care for her daughter for as long as she can remember. Their family first received a waiver for direct care services when her daughter was 3 years old. When asked what life would be like for her family if they had all the help they needed, LC sighed. "We haven't had it in so many years, I don't know what that would look like."

The lack of care has impacted every part of their family's life. The daily necessities that most people count on are a struggle for LC and her daughter.

"A lot of people take for granted that they have a 26-year-old, they're good to go, right? They can go to church. They can go to the store. They can maintain their employment. Those are luxuries for me."

Earlier this year, LC was forced to quit her job in order to care for her daughter. She could not find enough care workers to maintain her employment hours, but it was not for lack of trying. LC has gone down every avenue to find providers, from the Social Security Administration to Facebook groups.

She even took out an ad in the newspaper. Yet, her family only has 22 of the 168 hours in each week covered. Even during those hours, LC explained, her time still revolves around her daughter.

“Even if they’re at school, or go to a program, or whatever, it seems like you’re still working on things for them when they’re not here... still working on making sure her meds are picked up, her laundry is done, making appointments, paying her bills, any number of things that relate to her care... I don’t think people understand if they haven’t walked in our shoes.”

Even a small trip out of the house is a strenuous process for LC’s family. Swinging by the pharmacy requires her to pack up a suction machine, ventilator, diaper bag, and tube feeding equipment. LC must then pull her adult daughter in her wheelchair while also pushing a shopping cart. When deciding all the places they want to go, LC put it plainly. “Either she goes with us, or we don’t go. That could be something as simple as the grocery store or as big as a vacation.”

While LC has experienced the many difficulties of the direct care system, she tries to remain positive. “I wish people understood there’s a great reward in being... (a provider), to actually see the difference you’re making for the individual and their family. Your client isn’t just your client, your client is the whole family.” LC has seen many providers pushed out of the system by things like low wages, the complicated process to become a provider, or lack of training. If society values people with disabilities and their families, LC believes “We must incentivize people to do these jobs.”



Ohio House, District 66, Representative Sharon Ray
Ohio Senate, District 22, Senator Mark Romanchuk

Marcus and Cindy

Marcus: My mother, Cindy, was born on February 3, 1958, and was born and raised in the west of Cleveland. Later in life, she and my father relocated to Medina County. Cindy was born with cerebral palsy, making her unable to walk, along with a few medical problems, including incontinence. My father, who was my mother's primary caretaker, died of a sudden heart attack at age 53 in 2014. That's when the nightmare started. It took about 10 months to get a home health aide in the home. Social workers of Medina County along with Medicaid and Medicare went back and forth to get my mother a shower chair. She went a year without a proper shower, having to bathe in the kitchen sink.

Then came the numerous home health aides, aides that were physically and mentally abusive, aides who stole my mother's debit card and cash. The home health aides would often tell my mother that they were not paid enough, often showing up at inconsistent times and sometimes not at all. The home health aides were also untrained.

Cindy had a lift to get in and out of bed, but the aides did not know how to properly use the lift and would at times drop Cindy, resulting in her living in constant fear. Just before COVID hit, my mother's general health and wellbeing declined because of this lack of care. When COVID hit, there were no home health aides available in Medina County. Due to a lack of general care, care for her incontinence, and care for her home, Cindy's health further declined resulting in lengthy hospital stays.

“The problem is nobody wants to work for ten dollars an hour anymore. I don’t blame the aides and I don’t blame anybody, but our medical system has failed,” Cindy shared.

Marcus: Finally, the social workers said she had been in the hospital too long, and that her medical insurance would not pay for further hospital stays. This resulted in Cindy bouncing from a variety of short-term care nursing homes. In these several different nursing homes, Cindy was again not cared for and her health declined even further. Also, the conditions in these facilities were absolutely disturbing, just filthy.

Finally, the social workers of Medina County said that my mother had to get rid of her home and move into a long-term care facility. My father worked 2 and 3 jobs until his death. My mother lost everything – her home and her independence – due to a lack of home health aides. Her home was sold with the majority of her personal possessions still inside, as there was no room in her one-room nursing home.

Cindy recalls this nightmare the exact same way. “They took ME away, they took me away – I can’t be myself. I hope and pray you never have to be in one of these places. I’ll never give up because I’ll get to see my husband again.”

Marcus: Cindy now resides at the Avenue at Medina Care and Rehabilitation Center. Her incontinence is not cared for properly and her medication is given to her inconsistently, and at times not at all. During her time at the Avenue, her health has declined due to a lack of care to the point where she now needs a colostomy bag.

“They don’t have enough aides in here. It’s not getting better. I have to lay in pee all night and wait two or three hours in the morning to get changed. [Then the nurses wonder] ‘Why do I get a cold?’”, Cindy said about her lack of care at the Avenue.

Marcus: Cindy is defeated and depressed and feels that she has been put in a room to die, all because of a lack of home health aides and a lack of aides in the nursing home itself. I think the entire system for elderly care is broken. I am visually disabled and unable to physically assist my mother. I have written to lawyers, and news outlets and filed complaints with the Ohio Department of Health, but there has been no change. Honestly, I feel that no one within the system cares. The system only cares for the wealthy.

“I’m very proud of my son,” Cindy said when asked about Marcus writing her story. “He’s all I have. He took the time to write that letter, he’s grown but he’s still my baby.”