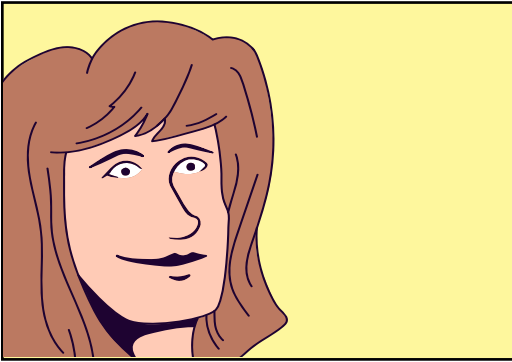


Provider Issues

for Individuals with
Developmental Disabilities



Introduction

People with developmental disabilities may need a range of supports and services to remain living in their community. A provider is an agency or independent contractor who can help with services such as homemaker and personal care (HPC), nursing, adult day programs, respite, transportation, homedelivered meals, or other services. Each provider must be certified by the Ohio Department of Developmental Disabilities (DODD) to provide these services under one of the three Medicaid Home and Community Based Services (HCBS) waiver programs. If an individual has a waiver, they can use the waiver to pay the provider an hourly rate for their services.

Waiver programs improve quality of life for people with developmental disabilities and their families and strengthen communities by providing essential supports. By reducing unnecessary placements in nursing homes and institutions, waivers are highly cost-effective, make best use of tax dollars, and help create more inclusive communities.

This issue brief discusses provider issues that affect services available to people with developmental disabilities, family economic security, and the providers themselves. The brief concludes with recommendations for solutions to the challenges faced by the providers who are essential to the success of waiver programs and people with disabilities and their families.



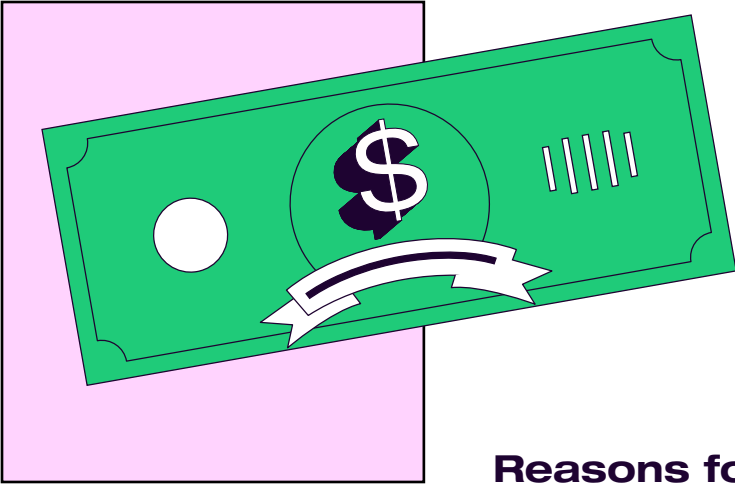


Provider Shortages

There is an increasing shortage of healthcare providers in the United States, creating a potential crisis for individuals with developmental disabilities. The 2020 “Case for Inclusion” found that states across the country face a caregiver “workforce in crisis” with turnover rates just under 70% in one state. Sean Luechtefeld of the American Network of Community Options and Resources said, “There isn’t a state in the nation where this is not a challenge.”¹

Without the help they require to remain independent, people with developmental disabilities who need assistance are at significant risk, contributing to unreasonably long waiting lists for services and leading many people to reconsider more expensive segregated care models, like nursing homes and Intermediate Care Facilities. According to the President’s Committee for People with Intellectual Disabilities (PCPID), “solutions to the direct support workforce crisis are critical to ensuring that people with intellectual disabilities can live, work and contribute to their communities.”²





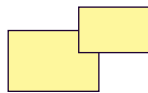
Reasons for Shortages

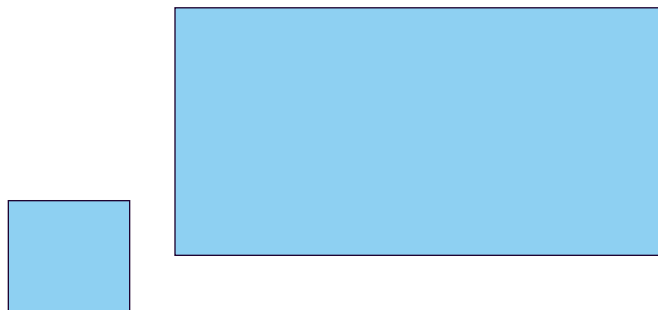
Pay and Lack of Benefits

Low pay rates and lack of employment benefits are one primary reason for the shortage of providers. According to the National Core Indicators (NCI) Staff Stability Survey of 2018, all direct-service providers' median pay was \$12 an hour.³ In Ohio, the median pay for all direct service providers was \$10.51 an hour.⁴

Ohio is behind many states in rates of pay for direct-service providers. In Ohio, the average yearly salary of a certified nursing assistant is \$27,040.⁵ 32 states pay certified nursing assistants a higher salary.⁶ For a single person, this salary is 211.91 percent of the federal poverty level. For a single parent with two children, this salary is 124.49 percent of the federal poverty level.⁷ In this example, the family would qualify for government benefits like Medicaid and food assistance because of their low income. In fact, more than one-third of nursing assistants are eligible for government benefits despite their hard work.⁸

According to the NCI Survey, almost 30 percent of direct-service providers were not offered employer-based health insurance. In the same survey, nationally, 65.4 percent of direct service survey responders were offered an employer-based pension plan.⁹ However, in Ohio, only 25.3 percent were offered the opportunity to participate in a plan.¹⁰



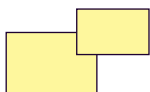


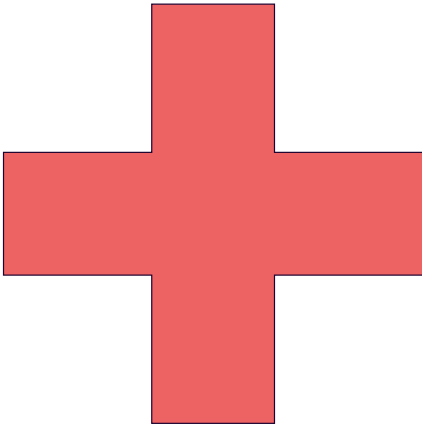
Injury and Illness

Working as a direct-service provider can be physically and emotionally demanding. Because individuals with developmental disabilities can also have physical disabilities, many service providers help with hands-on activities like bathing, lifting, transferring, toileting, mobility, and other physical activities. Most service providers work alone and may have no assistance in lifting or moving the people in their care. Between 40% and 48% of the home healthcare workers' time may be spent in poor posture combinations, including forward-bent and twisted postures associated with shoulder, neck, and back complaints.¹¹ People's homes do not typically have the equipment necessary to safely transfer or lift people, unlike in hospitals or nursing facilities, which is another factor that can lead to injury.

Working long hours can also contribute to high rates of physical injury for direct service providers. For example, being required to work overtime increased the odds of injury by 80 percent among nursing assistants.¹²

Further, individuals with developmental disabilities can also have behavioral issues that can be a risk to direct-service providers. According to the CDC, in 2007, America's 896,800 home healthcare workers reported a staggering 27,400 injuries, including muscular-skeleton injuries, accidents, and violence against providers.¹³ Direct service providers also risk getting sick from infectious diseases due to close contact with individuals with illnesses. The concern is even greater during public health crises like COVID-19.





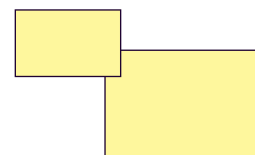
Violence, Harassment, and Discrimination

More than 2 million home healthcare workers across the U.S. provide personal assistance and health care support to older adults and people with disabilities in their homes and community based settings.¹⁴ Most direct service providers work two to three jobs to make ends meet,¹⁵ and the median age of home health care workers is 45.¹⁶

Besides the physical challenges of working with individuals with developmental disabilities, there are concerns about how providers are treated on the job. Direct service providers may experience violence directed towards them, inappropriately heavy workloads and levels of responsibility, incivility and bullying by coworkers, supervisors or managers, long hours and double shifts, increased physical demands of the work, and sexual harassment. In one study conducted in Oregon, home healthcare workers reported high levels of workplace physical violence (44%), psychological abuse (65%), sexual harassment (41%), and sexual violence (14%).

Race has been reported as a factor in direct-service providers' treatment and their overall job satisfaction. For example, according to the National Nursing Assistants Survey, Black nursing aides across job categories reported less perceived control, earned \$2.58 per hour less, and worked 7.1 hours on average more than their white counterparts.¹⁷

The challenges faced by home healthcare workers disproportionately affect women. Home healthcare workers are predominantly female (89%). Women of color are also disproportionately affected, with 24.4% of home healthcare workers self-identifying as Black or African American, 20.0% as Hispanic or Latino, and 4.4% as Asian.¹⁸ Over one-quarter of home healthcare workers were born outside the United States, but nearly 90 percent are U.S. citizens.¹⁹



High Turnover

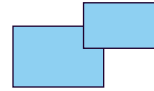
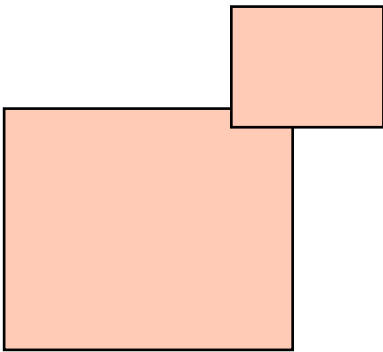
According to a report by PCPID, “low wages, scant benefits, limited training and lack of career advancement opportunities have resulted over the past 30 years in high turnover and vacancy rates throughout the long-term services and supports (LTSS) industry.”²⁰ Over a year, more than half of providers will leave their job. According to the NCI Staff Stability Survey of 2018, the yearly national turnover rate of direct-service providers is 51.3 percent.²¹ The high turnover rate of direct service providers is especially harmful to individuals with developmental disabilities, who generally thrive with routine and consistency.



Parents and Family Cannot Act as Paid Provider for Children

Homemaker and personal care services (HPC) often cannot be provided by a parent or family member for a child under 18 years of age. The Ohio Administrative Code explicitly states that parents of someone under 18 years old and family members living with them cannot be paid for HPC services for children receiving the SELF waiver.²² Under the Level One and IO Waivers, parents of minor children enrolled on those two waivers may be paid caregivers, if necessary and authorized through the person-centered planning process.²³ However, DODD typically only permits this in limited circumstances. On April 17, 2020, DODD announced that parents of minors could be paid HPC providers in limited circumstances and only during the COVID-19 pandemic. DODD stated this “would only be permitted when there is an immediate need and the regular provider is not available or able, and when an alternate provider is not available or able, to provide waiver services during the state of emergency.”²⁴ Under ordinary circumstances, parents and family members cannot act as paid providers for children, limiting their options when they cannot find providers to serve their children. When parents cannot find a provider to serve their children, one or both may be forced to stay at home to provide care. This eliminates parents’ employment options and puts enormous financial strain on most families.





Rural Issues

Finding a qualified service provider is especially challenging for individuals and families living in rural parts of the state. Although providers can get mileage reimbursed, it is more economically feasible to spend the time providing the greatest number of direct service hours, as opposed to traveling to provide fewer individuals with services.

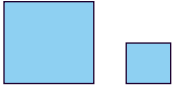
Emily's Story

Emily lives with her parents, Cori and Mark, in a rural county in Ohio. At age 14, Emily is very bright and capable but is challenged with sensory processing issues, communication problems, and difficulty feeding herself due to autism and general anxiety. Emily has been on the waiting list for a Medicaid waiver for nine years. During that time, Cori and Mark sought alternative community-based services and other funding sources to try to meet Emily's needs. Emily has been receiving Multi-System Youth funding temporarily and was recently approved for a SELF waiver.

Emily's parents want to find a provider so that Emily can learn to be more independent from her parents. Additionally, Mark works outside the home and Cori would like to work outside of the home, which has not been possible with Emily's needs.

Emily and her parents reside in a small, rural county. There are very few providers who serve their county. Cori and Mark have found a provider based in a large city willing to serve their county. However, the agency will need to find and hire qualified local staff to provide HPC and other services to Emily. The agency has a high demand in their urban county. It often does not have enough staff to cover the time required to drive and provide services without hiring additional people. Even with the SELF waiver, therefore, Emily will not have access to the assistance she needs to move forward more independently due to a lack of providers for rural areas.





Options for Families

Some families have found creative options to be able to meet their needs. For adults, family members and caregivers may become paid direct-service providers by becoming certified by DODD. Additionally, the IO waiver can be used by someone who lives with an adult receiving the waiver to compensate for their time spent caring for the individual. This service is called shared living.

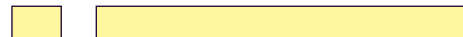
Coco's Story

Coco and her aunt, Bianca, moved to Ohio from a western state. Coco is 30 years old and has been living with her aunt, who is also her legal guardian, for most of her life. Coco has been diagnosed with Cerebral Palsy, Autism Spectrum Disorder, Obsessive Compulsive Disorder, Pica, Developmental Delay, and a severe intellectual disability. Coco is non-verbal and can become very upset when she cannot communicate her needs. Coco can walk on her own, but she relies on Bianca to bathe her, dress her, and change her diapers. Coco requires 24-hour care due to her disabilities. Coco cannot be left alone because she poses a risk to herself and others. Coco's behaviors include harming others and herself, picking at her skin, running away, and eating inedible or dangerous items. Coco also has insomnia and only sleeps two hours a night.

When Coco moved to Ohio, her County Board of Developmental Disabilities evaluated her and found her eligible for their services. The County Board also chose to place her on a Level One waiver, the lowest level of funding and support of the three waiver programs. Coco began using her waiver to pay for an adult day program, which provided Bianca some relief. Bianca, however, felt that she was the best person to provide Coco's care. Bianca became a certified independent provider for homemaker and personal care (HPC) services, which allowed her to receive some compensation for the extensive care she provides to Coco. This allowed Bianca to remain at home and care for Coco, rather than needing to find an outside job and hire a skilled service provider, which would likely cost more than she could make working outside the home. Because of Coco's extensive needs, funding for her Level One waiver ran out six months into her waiver span. Coco was then granted some temporary emergency funding.

With her ABLÉ attorneys' help, Bianca appealed a Waiting List Assessment decision that determined Coco had current, but not immediate needs. In her case, the hearing officer found that Coco had immediate needs (needs that would not be met within 30 days) and ordered the County Board to take immediate action. At that time, the County Board enrolled Coco in an Individual Options (IO) waiver.

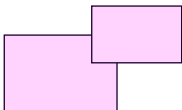
Under the IO waiver, Bianca could be compensated for more of her time caring for Coco through a service called shared living. As a shared living participant, Bianca gets paid a daily rate for her assistance on days when Coco does not use other services like respite, adult day programs, or homemaker and personal care services. This is a cost-effective and humane solution for a family facing big challenges and working hard to make ends meet.





Recommendations for Solving the Issues Discussed in this Brief

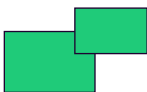
1. Increase pay rates and benefits for Home and Community Based Services providers.²⁵
2. Technical assistance and financial grants through federal agencies to encourage states to implement technology solutions in long-term services and supports, such as remote monitoring, sensors, robotics, and smart homes. Better use of technology would create efficiencies, reduce costs, reduce injuries, and support community living for people with intellectual disabilities.²⁶
3. The Ohio Department of Developmental Disabilities could deliver immediate relief with these policy changes:
 - Allow parents or family members to act as paid providers for both children and adult recipients in the Level One and IO waiver programs.
 - Allow Homemaker and Personal Care services to be conducted virtually to help address the shortage of providers, especially in rural areas.²⁷
 - Allow more than one household member to serve as a paid provider under the IO waiver's shared living service to help reduce the need for outside providers.





Citations

- ¹ <https://cronkitenews.azpbs.org/2020/02/17/disability-caregivers-workforce-crisis> at 2
- ² https://www.nadsp.org/wp-content/uploads/2018/02/PCPID-2017_-Americas-Direct-Support-Workforce-Crisis-Low-res.pdf at 8
- ³ <https://www.nationalcoreindicators.org/upload/core-indicators/2018StaffStabilitySurveyReport.pdf> at 4
- ⁴ Id at 44.
- ⁵ <https://www.registerednursing.org/>
- ⁶ Id.
- ⁷ <https://home.mycoverageplan.com/fpl-2020.html>
- ⁸ The National Nursing Assistant Survey: improving the evidence base for policy initiatives to strengthen the certified nursing assistant workforce. Squillace MR, Remsburg RE, Harris-Kojetin LD, Bercovitz A, Rosenoff E, Han B Gerontologist. 2009 Apr; 49(2):185-97.
- ⁹ Id. At 63
- ¹⁰ Id.
- ¹¹ <https://www.cdc.gov/niosh/docs/2010-125/pdfs/2010-125.pdf> at 16
- ¹² Khatutsky G., Wiener J.M., Anderson W.L., Porrell F.W. Work-Related Injuries among Certified Nursing Assistants Working in US Nursing Homes. RTI Press; Durham, NC, USA: 2012. Publication No. RR-0017-1204.
- ¹³ <https://blogs.cdc.gov/niosh-science-blog/2010/04/16/homehealthcare/>
- ¹⁴ <https://phinational.org/wp-content/uploads/legacy/phi-home-care-workers-key-facts.pdf> at 2
- ¹⁵ https://www.nadsp.org/wp-content/uploads/2018/02/PCPID-2017_-Americas-Direct-Support-Workforce-Crisislow-res.pdf at 16
- ¹⁶ <https://phinational.org/wp-content/uploads/legacy/phi-home-care-workers-key-facts.pdf> at 3
- ¹⁷ Hurtado D.A., Sabbath E.L., Ertel K.A., Buxton O.M., Berkman L.F. Racial disparities in job strain among american and immigrant long-term care workers. Int. Nurs. Rev. 2012;59:237-244. doi: 10.1111/j.1466-7657.2011.00948.x.
- ¹⁸ <https://www.cdc.gov/niosh/docs/2010-125/pdfs/2010-125.pdf> at 13
- ¹⁹ <https://phinational.org/wp-content/uploads/legacy/phi-home-care-workers-key-facts.pdf> at 3
- ²⁰ https://www.nadsp.org/wp-content/uploads/2018/02/PCPID-2017_-Americas-Direct-Support-Workforce-Crisis-Low-res.pdf at 12
- ²¹ [https://www.ancor.org/newsroom/news/nci-survey-direct-support-professional-turnover-now-available#:~:text=The%20newest%20National%20Core%20Indicators,\(DSPs\)%20is%2051.3%20percent.](https://www.ancor.org/newsroom/news/nci-survey-direct-support-professional-turnover-now-available#:~:text=The%20newest%20National%20Core%20Indicators,(DSPs)%20is%2051.3%20percent.)
- ²² OAC 5123-9-47(C)
- ²³ <https://dodd.ohio.gov/wps/portal/gov/dodd/about-us/communication/news/news-guidance-temporary-change-provide-waiver-services-minor-children>
- ²⁴ Id.
- ²⁵ https://www.nadsp.org/wp-content/uploads/2018/02/PCPID-2017_-Americas-Direct-Support-Workforce-Crisislow-res.pdf at 9
- ²⁶ Id.
- ²⁷ Homemaker and personal care services (HPC) help a person to become more independent while meeting their daily living needs. HPC services can include assistance with household chores and personal care, money management, and any other kind of support that improves a person's ability to express their opinions and choices. While some HPC services would be difficult to provide virtually, other services could be provided remotely. For example, you can teach someone to balance a checkbook or fold laundry virtually. Where possible and appropriate, an individual should be able to request that HPC services be delivered remotely.



Rebecca J. Steinhauser, ESQ.

Advocates for Basic Legal Equality, Inc.

Rebecca J. Steinhauser is the Managing Attorney for Healthcare and Public Benefits at Advocates for Basic Legal Equality. She is a graduate of the University of Dayton School of Law and has over 24 years of experience serving low-income communities.

Kara Ford, ESQ.

Legal Aid of Western Ohio

Kara Ford is a staff attorney at Legal Aid of Western Ohio. She is a graduate of the Moritz College of Law at the Ohio State University and practices in the area of public benefits and housing.



This project was made possible in part by a Grant from the Ohio State Bar Foundation.
The views expressed herein do not necessarily represent those of the Ohio State Bar Foundation.

