

VOR – A Voice Of Reason - is a national non-profit organization run by and for families of people with intellectual and developmental disabilities (I/DD) and autism. Founded over 40 years ago, our mission has always been to help families access the best resources for their loved ones. **VOR believes that in order to meet the individual needs of every member of this diverse population a full array of options and opportunities must be available for each person’s medical, intellectual, emotional, and behavioral challenges.**

Many of our families have individuals with the most severe degrees of I/DD and autism who reside in federally licensed facilities – often the only type of residence where their complex medical and behavioral needs can be met. These individuals benefit from a full range of services and 24/7 support. VOR supports choice in a continuum of quality residential options and services, including one’s own home, family home, community-based service options and Medicaid-licensed intermediate care facilities (ICFs) for individuals with intellectual disabilities.

- Over 6 million individuals have an intellectual disability.
- At least 1 in 6 children have one or more developmental disability.
- Data shows the number of people requiring long-term disability services is rising.
- Around 20% of I/DD individuals who are receiving Long-term Supports and Services (LTSS) live in a setting with more than 7 other residents.

For the 118th Congress, VOR supports several bills improving the lives and services available for the I/DD population.

- [S. 1332](#) / [H.R. 2941](#): Recognizing the Role of Direct Support Professionals Act
- [S. 1298](#): Supporting Our Direct Care Workforce and Family Caregivers Act
- [H.R. 553](#) & [H.R. 1296](#): Both protect employment options for individuals with I/DD.

VOR opposes:

- [S. 533](#) / [H.R. 1263](#): Transformation to Competitive Integrated Employment Act: These bills effectively eliminate a highly successful program that creates a workspace for many in the I/DD community.

VOR would like these bills **expanded** to include necessary services for the *MOST* vulnerable I/DD individuals, in addition to those with less severe physical and mental healthcare needs:

- [S. 100](#) / [H.R. 547](#): Better Care Better Jobs Act
- [S. 762](#) / [H.R. 1493](#): HCBS Access Act

As a voice for the most vulnerable within the I/DD population, VOR is always available as a resource for you. We appreciate your efforts to improve services and support available to meet the physical and mental needs of *ALL* individuals in the disability community and look forward to working with you to meet these legislative goals.

Addressing the Workforce Crisis

Critical Disability Care Services are Scarce

The American system of Developmental Disability Services (DD) relies on an extensive workforce of caregivers. In addition to the highly trained doctors, dentists, psychiatrists, nurses, and behavioral and physical therapists who work with people with intellectual disabilities and autism (ID/A) and the aging populations, there is a vast workforce of Direct Support Professionals (DSPs) who perform the daily tasks of caring for, and caring about, our most vulnerable citizens.

DSPs are truly the backbone of the DD system.

There is a critical shortage of DSPs. The national turnover rate, with people leaving the job in less than one year, stood at around 45% nationally from 2016 -2020, and was as high as 80% in some states.^{1, 2} Across the country, providers of Long-Term Supports and Services (LTSS) including nursing homes for the aging population, group homes and in-home services, intermediate care facilities (ICFs), day programs for people with ID/A, and nursing homes for the aging population have been forced to cut back services or close facilities due to this shortage. According to a 2023 report from ANCOR, 83% of providers are turning away new referrals, 63% are discontinuing programs and services, and 55% are considering closing additional services. 92% of providers are struggling to achieve quality standards.³

Long hours, the lack of any defined career path or opportunity for advancement, poor training and lack of certification standards, and the ever-present risk of personal injury when a client has an aggressive or violent behavioral episode all contribute to the high turnover rates.

The biggest deterrent to hiring new DSP workers is the low pay.

Many DSPs are paid through the Centers for Medicare and Medicaid Services (CMS) and only receive the federal minimum wage of \$7.25 per hour.

That's about the average cost of a cheeseburger in the U.S., and it is not a living wage. Even when state legislatures vote every two years to bring the wage up to their state minimum wage, or higher, to try to remain competitive, they still fall short of what fast food chains or big box stores offer. These workers deserve more. They help with personal hygiene, toileting and diapering adults, brushing their teeth, shaving, feeding special diets and pureeing food, inserting J-tubes and G-tubes, monitoring for Pica and self-injurious behaviors, handling seizures and violent outbursts. They offer love, devotion, and understanding to people who don't easily communicate. DSPs deserve pay that reflects their work.

The Build Back Better Act and the HCBS Access Act have provisions that would increase salaries and provide training for DSPs who work in HCBS-funded settings *only*. This leaves out a considerable number of DSPs, those who work in ICFs, non-HCBS nursing facilities, non-HCBS day programs, and more. These service providers all draw from the same pool of workers. Non-HCBS providers would be unable to compete for employees against the higher wages offered by HCBS providers – leaving our most medically complex individuals with I/DD and our elderly population without the care they need.

Policy changes should ensure necessary services are available to all within the aging and disability community. Policy changes should provide the stability this system needs to avoid costly consequences for the government, providers, and most importantly beneficiaries.

VOR urges you to strengthen this healthcare sector by amending the above legislation to ensure the severely disabled and elderly have DSPs care in ALL the settings where they receive services.

How Congress Can Help:

1. Increase wages and pay scales equitably for ALL Direct Support Professionals who work with people receiving services through Medicaid.

DSP employees should be treated equally regardless of the type of facility in which they serve, or which funding stream, or silo, within the CMS system supports them. Current legislation should be amended to reflect this.

Further, since wages for DSPs are currently tied to the federal minimum wage, there are several approaches for updating this policy. VOR supports dialogue that works to develop the policy and legislation that supports employees, employers, patients, and the states.

2. Support a career path and certification programs for Direct Support Professionals.

Serving as a caregiver is more than a job. It is a profession. A profession within the American Health Care System. Let's treat it as such. As with any other professional service, there should be rewards for experience and length of service. There should be certifications for training in different methodologies and for gaining understanding of how different intellectual disabilities manifest and change through life stages. And there should be a career path into other health care professions, such as credit towards a nursing degree or an administrative position.

3. Create a Standard Occupational Classification for Direct Support Professionals.

We ask Congress to enact legislation that will direct the Bureau of Labor Statistics and the Office of Management and Budget to establish a standard occupational classification (SOC) for Direct Support Professionals. SOCs enable the DOL to collect data and influence policymaking to establish standards and improve the ability of providers in recruitment, training, retention, and advancement of a quality workforce.

4. Require best practices for high standards in hiring Direct Support Professionals.

Background checks are required in all states, but the standards vary greatly. More thorough background checks reduce the potential for instances of abuse and neglect of clients. They also help reinforce the safety of other caregivers and give them assurance that their coworkers have everyone's best interests at heart.

We suggest that all states use the FBI's IAFIS database, and that there be a uniform code for hiring DSPs, so that all people in all states have equal protection against abuse and neglect. One example of a well-designed system is currently in use in Ohio.⁴

We cannot emphasize enough how drastic this situation is. Aging parents and guardians leaving the workforce to be caregivers is not an answer to this crisis. Please act now.

¹ *President's Committee for People with Intellectual Disabilities, Report to the President 2017, Full Report, p. 5*
https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

² *National Core Indicators, National Association of State Directors of Developmental Disabilities Services (NASDDDS) and Human Services Research Institute (HSRI) - 2020 Staff Stability Report, p. 30*

https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiP-bWO2af-AhUtF1kFHQOIBOIOFnoECBYOAAQ&url=https%3A%2F%2Flegacy.nationalcoreindicators.org%2Fupload%2Fcore-indicators%2F2020StaffStabilitySurveyReport_FINAL.pdf&usq=AOvVaw0tYbPr2wZJ5z3QoNAjwEgg

³ *The State of America's Direct Support Workforce Crisis 2022*. Alexandria, VA: ANCOR, 2022.
<https://www.ancor.org/resources/the-state-of-americas-direct-support-workforce-crisis-2022/>

⁴ Ohio Administrative Code (OAC): 5123:2-2-02: Background investigations for employment.
<https://codes.ohio.gov/ohio-administrative-code/rule-5123-2-02>

Available for download at: <https://dodd.ohio.gov/forms-and-rules/rules-in-effect/5123-2-02>

Strengthen Employment Options for the Disability Community 14(c) & Competitive Employment Choice

VOR unconditionally supports programs that create opportunities for competitive, integrated employment (CIE) for people with intellectual and developmental disabilities (I/DD) who choose such work. What we do not support is coupling CIE with phasing out or eliminating section 14(c) of the Fair Labor Standards Act. That program permits employers to pay commensurate wages to a defined group of individuals with I/DD whose medical, behavioral and intellectual challenges are not able to be realistically accommodated by employers in a competitive work environment. 14(c) employees make an informed choice to participate in these programs.

14(c) employees are voluntarily participating in a program that enriches their lives.

Section 14(c) authorizes the issuance of special certificates that permit employers to pay individuals with I/DD less than the federal minimum wage when their level of productivity is so low as to make them noncompetitive in the general workforce. Employers, who voluntarily participate, are required to make special accommodations for their intellectual, physical, behavioral, and mental illness challenges, giving thousands of individuals with I/DD the opportunity to work in a specialized environment that nurtures them and fits their abilities. Under this program, people with I/DD earn wages that are commensurate with their level of productivity and their capacity to work. The 14(c) programs are carefully regulated by the Wage and Hour division of the U.S. Department of Labor. The application process is lengthy and must be reviewed every two years. Employees are tested twice each year to ensure that their wages are adjusted to correspond to their productivity and skills. Without 14(c) certificates, these people would lose any opportunity to work.

Individuals who are covered by 14(c) certificates cannot reasonably be accommodated in most conventional work environments. Some have medical conditions, including occasional seizures. Others have behavioral disorders and are prone to self-injurious or aggressive behaviors. Still others require help toileting. The vocational centers that employ them provide a specialized environment adapted to individuals with I/DD who desire to work, individuals who have intellectual and physical skills as well as intellectual and physical disabilities.

These vocational centers and commensurate wage programs provide more than employment: Job coaches help employees develop their skills. The coaches have also been trained to handle the physical, medical, and behavioral challenges as they arise. Earned wages, though appreciated, are not the substantive reward for these individuals. The individuals who work in these 14(c) programs thrive by having the opportunity to use and improve their skills, alongside their peers, in a safe and therapeutic environment. In fact, studies have found that over 97 percent of 14(c) employees want to continue working with this program. The 14(c) programs afford workers opportunities to build self-esteem, develop friendships, and engage in their communities.

This is not an either/or situation. This should be both/and. Congress can strengthen the competitive job market and increase programs that support work opportunities for many in the I/DD community. The answer is simple: Pay minimum wage to people with I/DD who can, with reasonable accommodations, perform at a competitive productivity level and ensure the continuation of the 14(c) program for those who cannot.

VOR asks Congress to expand, not decrease, employment opportunities for all people with I/DD.

Please support [H.R. 553](#) & [H.R. 1296](#) to ensure the 14(c) program is available as an employment choice for those who qualify to participate.