VOR

A Voice Of Reason
Speaking Out for People with
Intellectual & Developmental Disabilities

VOR’S 2026 LEGISLATIVE INITIATIVE

A VOICE OF REASON
FOR
THE 119TH CONGRESS

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Speaking Out for People with
Intellectual & Developmental Disabilities

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Who We Are

VOR (A Voice Of Reason) is a national non-profit organization founded in 1983 by families of people with intellectual and developmental disabilities (I/DD). Our mission has always been to advocate for high quality care and human rights for all people with intellectual disabilities and autism (ID/A). Our members are families whose loved ones are too severely impacted to ever speak for themselves, most of whom are fully grown adults who have the mental capabilities of infants or toddlers who will not experience significate medical or functional improvement over time. They require around-the-clock care by skilled clinicians and caregivers. Their care, quality of life, and survival are, quite literally, dependent upon access to services provided through Medicaid programs.

Many of our family members are non-verbal. Some have self-injurious behaviors, while others can be aggressive or have violent outbursts. Some have autism, many have low IQ, still others have medical, physical, or sensory challenges. Some have dual diagnoses of ID/A and severe mental illnesses.

Our Advocacy

VOR advocates for **Choice** in residential options and employment opportunities. We need a system that supports and invests in a full range of services to meet the needs and aspirations of every member of the many and various ID/A communities. We understand that Choice is both a privilege and a responsibility – that to expect to be able to make one’s own choices, one must also respect the choices made by others, even when those choices may not be the ones we might have made. Choice means respecting the challenges we all face, understanding that there are limited options available, and acknowledging that everyone and every family is unique. While most of VOR’s family members are on the severe/profound end of the spectrum, we understand, empathize, and advocate for the needs of *all* people with ID/A, their families, and their caregivers.

How Congress Can Help

As you will see in the following pages, there are practical, bipartisan steps legislators can take to improve services for this vulnerable population while reducing waste, fraud, and abuse in Medicaid. We look forward to partnering with you to ensure our community receives services they qualify for and need for their health and safety.

Changing Demographics Call For A Corresponding Balance Of Services

Over the past fifty years, the ID/A population has grown dramatically, and so have the complexity of their needs. Autism diagnoses have increased at an alarming rate, most notably at the severe and profound end of the spectrum. The number of people seeking both Home- and Community-Based Services (HCBS) and placement in intermediate care facilities (ICFs) has risen sharply.

The Supreme Court's decision in *Olmstead v. L.C.* states, "[W]e recognize… the States' need to maintain a range of facilities for the care and treatment of persons with diverse mental disabilities, and the States' obligation to administer services with an even hand." [1] Justice Kennedy added, citing from an *amicus curia* from VOR, "Each disabled person is entitled to treatment in the most integrated setting possible for that person—recognizing that, on a case-by-case basis, that setting may be in an institution." [2]

Yet funding priorities have not kept pace. Twenty-five years ago, CMS appropriated 90% of its funding to ICFs. Today, over 90% of Medicaid spending for people with ID/A goes to HCBS, with less than 10% going to ICFs. Over the years, what started as an attempt to rebalance services has evolved into a deliberate movement to erode and eliminate the ICF system, regardless of the fact that tens of thousands of individuals still need and apply for ICF care.

Claims that the cost of housing one person in an HCBS setting is lower than the cost of housing one person in an ICF are deliberately misleading. Apples to oranges.

Comprehensive studies have repeatedly shown that the cost of care and services for high acuity individuals in ICF settings is significantly lower than the cost to provide equivalent care and related services in HCBS settings. there are few providers offering high-acuity services in HCBS settings.

Unlike most health care systems, which triage to serve the most severe cases first, CMS' delivery of long-term services and supports to people with ID/A prioritizes serving those best suited to community living, while providing services for high-acuity individuals last. To enroll for HCBS services, families are required to waive their right to care in larger congregate facilities like ICFs—often without ever having been informed those options exist. In some cases, parents have been told that no ICF beds are available, and that they must sign the waiver to receive *any* services.

Re-balance, Re-invest, and Re-Open

One in thirty-one children born today have autism. One quarter to 1 third of those children show signs of severe/profound autism. HCBS is not capable of providing the level of care that many of these individuals will require. It's time we **re-balance** the system once again, **re-invest** in building new ICFs, and **re-open** ICFs to new admissions to meet these changing demographics.

We ask members of Congress to download this recent cost comparison from Massachusetts:
https://www.vor.net/legislative-voice/legislator-toolkit/ma-cost-comparison

We also ask members to arrange a visit to an ICF in your state, to meet the residents in order to better understand their level of need, and to see the quality of services provided

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[1] Olmstead v. L. C., 527 U.S. 581 (1999) p. 597 https://supreme.justia.com/cases/federal/us/527/581

[2] *Ibid,* p. 605

Addressing the Critical Shortage of Direct Support Professionals (DSPs)

Across the United States, a workforce of over 4.5 million people provides daily care to people with disabilities, veterans, and the aging community. An estimated 1.3 million to 2 million of these caregivers are Direct Support Professionals (DSPs), who serve as the backbone of care for individuals with intellectual and developmental disabilities and autism (ID/A). These professionals provide services that help individuals engage with their communities, attend day programs, and receive daily care in group homes, ICFs, and nursing homes.

There has been a critical shortage of DSPs for decades. One in eight DSP positions remain vacant. The turnover rate for DSPs hovers at around 45% nationally, with some states reaching a level exceeding 75% per year. People with ID/A rely on consistent care and long-term relationships with caregivers. The instability of this workforce is detrimental to the quality of life for our most disabled individuals.

It has been estimated that another 1 million DSPs will be needed in the next few years, as the number of people requiring ICF and HCBS services continues to rise.

- The CDC reports that 1 in 31 children is now diagnosed with autism.
- Over 7 million Americans are currently living with Alzheimer's
- As parents who serve as family caregivers age, they will need HCBS or ICF placements for their adult children with ID/A.
- Currently, over 600,000 individuals are on ID/A waiting lists for Medicaid services, with some people waiting over 10 years to receive services.

There are many reasons for this shortage, the primary one being consistently low wages. below that of unskilled or minimally trained workers in big box stores or the fast-food industry. Many DSPs lack healthcare benefits although they often face physical risks on the job. Furthermore, there is no federally recognized classification for DSPs, no federally recognized training or certification, and there is no path to career advancement.

How Congress Can Help

- Demand DSP wages and benefits are competitive with the professional workforce.
- Establish a national certification standard and professionalize the field.
- Implement federal training requirements and strengthen background checks.
- Support career paths that would allow DSPs to transition into health professions.

Please co-sponsor:

***H.R.6137* / *S.3211* - *The Recognizing the Role of Direct Support Professionals Act*,** which would require the Office of Management and Budget to revise the Standard Occupational Classification system to establish a separate code for Direct Support Professionals.

H.R.8541* - *The Long-Term Workforce Support Act, which addresses critical shortages by improving compensation, training, and safety for workers caring for seniors and people with disabilities.

Meaningful Daily Activities and Employment Opportunities

People with ID/A thrive when they regularly participate in meaningful daily activities that stimulate their minds, exercise their bodies, hone their skills, and give them a sense of accomplishment and a feeling of being part of their communities. Their abilities and behaviors regress when they have too much idle time or if daily programs fail to engage their interests.

Day Programs

Most of VOR's family members are on the severe/profound end of the scale. They participate in day programs. The better programs offer activities like swimming, group exercise, horseback riding, music or art therapy, and relaxation practices like yoga or Tai Chi. Ideally, every residential setting for people with severe/profound ID/A should offer these programs. Unfortunately, not all facilities are able to provide them, especially smaller HCBS group homes or underfunded ICFs.

Competitive Integrated Employment

Around the age of 21, school and other childhood programs end, and families must find adult programs for their loved ones. A few people with autism go on to college or careers that draw on their unique talents. But the first choice for most young adults with ID/A is competitive integrated employment (CIE), usually a job with a local employer, designed to accommodate someone with ID/A, paying minimum wage or better, and working alongside non-disabled coworkers.

Unfortunately, there are far too few such opportunities, The unemployment rate for people with ID/A remains significantly higher than for non-disabled individuals. Employers tend to seek candidates best suited to the work at hand and who can most easily interact with their coworkers.

A Third Option: Sheltered Workshops, 14(c) Programs, and Compensatory Wages,

There is a cohort of individuals with ID/A whose abilities and challenges place them between those who go to day programs and those hired in CIE. They have skills, and they want to work, but their challenges make it difficult for most employers to accommodate them. Perhaps they have a seizure disorder, or occasionally need assistance changing their adult diapers. Their social skills may be off-putting to the public or their fellow employees. Some might simply prefer the company of their peers over being 'different' from others on their job. Sheltered workshops meet these individuals where they are, offering meaningful daily activity and compensatory wages in accordance with Section 14(c) of the Fair Labor Standards Act.

These are voluntary programs. No one is forced to work in a sheltered workshop. Individuals choose how much or how little they work, and the workshops offer alternative activities if a participant doesn't feel like working their regular job. No one can be fired for low productivity or failing to meet quotas. All work is supervised by job coaches trained as DSPs.

14(c) programs are strictly regulated by the Wage and Hour Division of the Department of Labor. Employers must regularly apply for re-certification. Compensatory wages are tied to productivity—measured against the output of non-disabled workers—and are re-evaluated every six months. Some employees earn above minimum wage for certain work they perform. But to most, wages are not as important a consideration as the work, the environment, and the community.

Unfortunately, there is a movement to phase out or eliminate 14(c) employment opportunities. Several states have forced the closure of sheltered workshops. Most people who have been forced out of these jobs have not entered the CIE workforce or have received only a few hours of employment per month. Others have been consigned to day programs, where they may regress.

We ask that Congress expand opportunities for individuals, not eliminate them. Surveys have shown that there is a 97% approval rating among people who regularly participate in 14(c) programs. So why not let those who enjoy these jobs be the ones to choose?

We urge members of Congress to visit a sheltered workshop in their state.

We also ask that you **cosponsor *H.R.8736* - Restoration of Employment Choice for Adults with Disabilities Act,** which would amend the Rehabilitation Act of 1973 to ensure workplace choice and opportunity for adults with intellectual disabilities.
https://www.congress.gov/bill/119th-congress/house-bill/8736

Please ***oppose*** bills that would phase out and eliminate 14(c) programs, while offering no concrete assurances that those who are displaced will receive equivalent hours in CIE:
H.R.4771 **/** *S.2438* **– Transformation to Competitive Employment Act**
H.R.2743 / S.1332 **– Raise the Wage Act** *(Contains language to eliminate 14(c) programs)*

The HCBS Settings Rule

The Medicaid Home and Community-Based Services (HCBS) Settings Rule (42 C.F.R. § 441.301(c)), issued by CMS in 2014, was intended to expand autonomy and community integration for individuals with ID/A. While well-intentioned, its implementation produced unintended consequences, particularly for those individuals with complex medical, physical and mental needs, by narrowing the available care options and stifling innovation in building new facilities and creating new models.

The rule has discouraged the development of settings such as farmsteads, intentional communities, and campus-based models. These environments are often sought out by individuals and families who seek settings tailored to higher levels of need. In limiting these options, the current rule risks leaving some of the most vulnerable populations without suitable alternatives.

Under the Settings Rule, providers have been unable to build homes with enough proximity to each other that they may build an economy of scale that gives them flexibility in staffing homes and allows them to hire nursing staff to cover homes within a close proximity to each other. Furthermore, the Settings Rule has been interpreted differently by different states, making it more difficult for providers to understand what they can and cannot build from one state to the next.

The Settings Rule claims to promote "person-centered planning", but in practice it restricts planning options. It promotes integration into the broader community and competitive integrated employment, while denying the fact that many people prefer to live and work among their peers. It claims to protect from restraints and seclusion, yet fails to enforce these laws in group homes, day programs, or in schools.

In short, the HCBS Settings Rule undermines choice and imposes restrictions on options that should be available to individuals, families, and providers. It is ideologically biased to favor the aspirations of people at one end of the spectrum while limiting options beneficial to those with more severe and profound intellectual disabilities.

We ask members Congress to petition CMS leadership to rescind the HCBS Settings Rule.

Protection and Advocacy Agencies:
Failing to Protect People with ID/A from Abuse and Neglect

Under the DD Act *(Public Law 106-402, October 30, 2000)*, every state is granted an allotment to create and maintain its own Protection and Advocacy (P&A) system. P&As are federally funded by the Department of Health and Human Services (HHS), through the Administration for Community Living (ACL).

Section 143 of the DD Act:

- Provides these agencies with the legal authority to advocate for the rights of individuals with disabilities.
- Provides them with the authority to investigate incidents of abuse and neglect of individuals with developmental disabilities if incidents are reported to the system or if there is just cause to believe incidents occurred.
- Report annually to the Secretary of HHS on their goals, priorities, and activities.
- Report annually to the [ID/A] public and provide a grievance procedure to ensure that people have full access to the system.

VOR contends that the current P&A system misinterprets th mission as an “integration mandate”, rather than taking action to protect the full ID/A community it was empowered to serve.

While P&As have long championed moving people out of ICFs, often against the wishes of families and guardians, they have a poor track record of protecting those same individuals from abuse and neglect once they have been moved into HCBS community settings. When the DD Act was created in 2000, most people with ID/A lived in ICFs; today, the majority reside in the community. State and federal oversight has failed to keep pace with this shift.

In recent years, newspapers from Illinois, New Jersey, and New Hampshire have shown that multiple incidents of abuse and neglect in HCBS group homes have been reported to P&As with no action taken. We believe that the mandate for P&A’s must clearly focus on protecting *all* people with ID/A from abuse and neglect, and that every state’s P&A should be accountable to that state legislature that designates and funds them, and to provide a formal grievance procedure for the community that they have been appointed to serve.

ACL is well within its authority to direct states to increase and improve audits, inspections and more at a scale and pace that is more efficient and effective than at the individual state level. The Office of Disability Services Innovation (ODSI), under the ACL umbrella, directly manages the P&A program and should exercise its federal responsibility to direct P&A’s to ensure the safety and well-being of people with ID/A in all settings. Their oversight is leaving most of our nation’s most vulnerable with no protection.

The DD Act was created by Congress, and Congress has the authority to ensure it is being carried out in accordance with the law.

VOR is requesting that Congress direct the ACL and ODSI to improve transparency of its role in overseeing HCBS residencies. Such oversight would include increased visits to HCBS residencies, unannounced visits to HCBS residencies, and submitting regular reports of their activities to state officials and the public.

*** Extra Credit ***

The Unserved: People with ID/A, Mental Illness, and/or Severe Behaviors

Individuals who present with symptoms of a developmental disability *and* with challenging behaviors are ill-served by existing community and institutional resources. These patients are medically complex, difficult to diagnose correctly, and virtually impossible to place, especially when they reach adulthood.

Traditional programs established for people with developmental disabilities often refuse service on the grounds that such programs are not staffed or trained to handle patients who may be aggressive or engage in self-harm. Mental health programs may decline to admit or serve these patients on the grounds that the patients have developmental disabilities, not a psychiatric illness.

Patients with overlapping mental, behavioral and/or physical needs frequently fall through the cracks in a service system that is not designed to care for them properly. These individuals who do not get the necessary help end up cycling through expensive inpatient hospital admissions, boarding in hospitals indefinitely for want of appropriate outpatient placements, or worse still, landing in prison settings or homeless shelters.

We have no plan to provide long-term care for these dually-diagnosed individuals. The failure to establish appropriate systems to support these individuals is short-sighted. It is also expensive, both in human terms and in monetary terms.

Currently, some state-operated intermediate care facilities for individuals with intellectual disabilities are offering housing segregated housing for these individuals. But while we understand that this is an alternative to hospitals or jails for these individuals in need, ICFs/IID are not the appropriate solution. They are not staffed sufficiently to deal with this level of aggression, putting both the residents and the staff themselves at risk. Yet ICFs and forensic care facilities may serve as a better model than HCBS settings.

To address this gap in services, we must better define, diagnose, and identify these individuals who fall outside of the current categories, update Medicaid funding to maximize state and federal dollars for the care of this population, and develop cross-agency collaboration within HHS as well as state agencies. We will need to create new models for long-term care facilities and/or housing. These residential models will require 24/7 staffing, with significantly higher staffing ratios than provided in regular HCBS facilities. Entry-level staff would require training comparable to that required of psychiatric technicians or mental health therapy aides in psychiatric hospitals.

For more information on this issue, please go to:
https://www.vor.net/legislative-voice/legislator-toolkit/unserved-individuals