



## **Meet VOR:** *A Voice of Reason, speaking out for people with Intellectual and Developmental Disabilities*

VOR is a national non-profit organization, founded in 1983, that advocates for high quality care and human rights for *all* people with intellectual and developmental disabilities (I/DD). Our membership is mostly comprised of families of individuals with severe or profound intellectual disabilities, often complicated by significant medical, psychological, and behavioral conditions. Many of our loved ones are non-verbal and non-ambulatory. Many engage in self-injurious behaviors. They often require 24/7 care, by well-trained and caring direct support professionals.

**Our family members constitute a minority within a minority. They represent about 5% of the population of individuals with I/DD.** The home and community-based settings that work for many people with I/DD often fail to meet the needs of these severely disabled, vulnerable individuals.

To acknowledge the extensive range of needs and aspirations of *all* members of this diverse population, **VOR supports Individual and Family Choice, and a Full Continuum of Care.** To have choice, there must be a full range of quality options, tailored to meet the intellectual, psychological, behavioral, and physical needs of this diverse population. **One size never fits all.**

While we support the goals of those who aspire to integrate into the society around them in their choices of residence, education, and employment, we also support the needs of those who would be endangered in an under-protected environment, who can never integrate fully because they cannot perform the simplest of daily skills, like brushing their teeth, washing, toileting, or verbalizing their needs, their desires, their agitation, or their anger. **The goals of one group should never be placed at odds with the needs of the other.** We support all residential options, including the individual's own home, family home, group homes, intentional communities, and larger congregate settings, such as public and private Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID, or ICFs).

By the same principle, **we support a full range of employment opportunities** for people with I/DD. We support the drive for integrated, competitive employment and laud the proliferation of programs aimed at helping people with intellectual disabilities achieve their full potential. But we oppose the movement to eliminate center-based employment and compensatory wages under Section 14(c) of the Fair Labor Standards Act. People who will never have the capacity to compete in the open job market need an opportunity to participate in employment appropriate to their abilities. Our family members enjoy this level of work, the peer environment, and the opportunity to be productive. The movement toward competitive employment for some should not mandate the elimination of programs that work for others.

**There is no singular solution that is appropriate to all individuals with I/DD.** Yet, this is the premise of policies promoted by many powerful advocacy groups. This is a dangerous assumption, especially for the most vulnerable. They need protection, and we are asking for your help.

## VOR's ASKS:

### PLEASE SUPPORT

1. Medicaid Funding for people with Intellectual and Developmental Disabilities (I/DD) without changes that would reduce these critically necessary funds.
2. The HEADs UP Act of 2019. This bill would designate people with I/DD as a Medically Underserved Population, providing them with better funding for primary and specialized care, incentivizing new research, and authorizing more favorable reimbursement rates for providers who treat this population.
3. The Autism CARES Act of 2019, which would extend the Autism CARES Act of 2014 and provide for further research into the causes, diagnosis, and early and ongoing detection, prevention, and treatment of autism spectrum disorder. The bill would also reduce disparities within the autism community by improving access to clinical services for youth and adults from diverse racial, ethnic, geographic and linguistic backgrounds.
4. ALL people with Intellectual and Developmental Disabilities by supporting a full range of residential care and employment options.

### PLEASE OPPOSE

1. The Disability Integration Act of 2019. This act would eliminate individual or family choice of residential settings for individuals with I/DD, strain federal and state budgets for Medicaid, and overturn key provisions in the landmark 1999 Supreme Court Decision in Olmstead.
2. The Raise the Wage Act and the Transformation to Competitive Employment Act, as long as they contain provisions that would eliminate work opportunities for some individuals with I/DD whose disabilities are so severe they are unable to perform tasks sufficient to warrant the payment of a minimum wage.

## THE HARMFUL EFFECTS OF THE DISABILITY INTEGRATION ACT (DIA)

H.R. 555 / S. 117

VOR urges Members of Congress to consider the harmful effects the DIA would have on severely disabled people, state budgets, and legal precedent before taking any action:

- The DIA would eliminate the option for individuals with disabilities and their families to choose to receive care in an Intermediate Care Facility (a so-called “institution”). This Medicaid-certified federal program, which is jointly funded with the states, provides comprehensive care with extensive oversight for society’s most intellectually disabled individuals. In turn, the legislation would put tremendous pressure on the Home and Community Based Services (HCBS) program, another federal-state program, which does not provide a similar level of care for individuals with complex needs.
- The DIA is unaffordable. As noble as providing services for every person with intellectual and developmental disabilities (I/DD) on waiting lists may be, the cost of doing so would be prohibitive for both state and federal budgets. The proof of this would lie in a CBO score, which has not been requested since the legislation was first introduced in the 115th Congress.
- The DIA would overturn a key portion of the landmark Olmstead decision, in that it specifically states that it would eliminate the option to choose institutional care (see pp. 21 & 32-33). As the Court said:

*"Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, 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." (Olmstead v. L. C., 527 U.S. 581, at 597)*

*"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." (Olmstead v. L. C., 527 U.S. 581, at 601-602)*

Instead of pursuing unrealistic discriminatory legislation, we would encourage the Congress to provide additional funding for all residential options for individuals with I/DD and to target funds to alleviate the dangerous shortage of Direct Support Professionals whose services are essential to serve this and the elderly population.

In sum, before you consider taking any action on the DIA, VOR asks that you read the entire bill. We believe a fair reading supports our contentions that it would overturn key portions of Olmstead, marginalize our most vulnerable citizen with I/DD, limit their families’ choices for appropriate residential care, and overwhelm states budgets.

**We urge you to oppose the Disability Integration Act.**

## Olmstead: Protecting the Rights of All Individuals with Intellectual and Developmental Disabilities

*Olmstead v. L. C., 527 U.S. 581 (1999)*

The Supreme Court's decision in *Olmstead v. L. C.* [527 U.S. 581 (1999)] has been frequently misrepresented as a mandate for inclusion, a simple, one-sided declaration that all individuals with intellectual and developmental disabilities (I/DD) must live in community-based settings. **This is not true. There is no inclusion mandate in *Olmstead*.** Rather, the Court's determination in *Olmstead* supports both the right to an inclusive environment and the right to institutional care, based on the need and desires of the individual. *Olmstead* guarantees choice for all individuals, their parents, and guardians. *Olmstead* requires that those who are moved from institutional care to smaller, community-based group homes meet three distinct criteria to determine the appropriate residential setting. There is no mandate to deny access to institutions, to close institutions, nor to place at risk any individuals who need and choose institutional care.

### **The Supreme Court recognized the need for States to maintain a range of facilities for the diverse needs of persons with developmental disabilities:**

*"Unjustified isolation, we hold, is properly regarded as discrimination based on disability. But we recognize, as well, 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."*<sup>1</sup>

*"We emphasize that nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings. . . Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it."*<sup>2</sup>

### **The majority opinion revealed the need for standards in determining the appropriate level of care:**

*"Consistent with these provisions, the State generally may rely on the reasonable assessments of its own professionals in determining whether an individual 'meets the essential eligibility requirements' for habilitation in a community-based program. Absent such qualification, it would be inappropriate to remove a patient from the more restrictive setting."*<sup>3</sup>

### **The Court set conditions before the State is required to move individuals to the community:**

*"[U]nder Title II of the ADA, States are required to provide community-based treatment for persons with mental disabilities [1] when the State's treatment professionals determine that such placement is appropriate, [2] the affected persons do not oppose such treatment, and [3] the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities."*<sup>4</sup>

### **A plurality of Justices concurred:**

*"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk. . . Some individuals . . . may need institutional care from time to time 'to stabilize acute psychiatric symptoms'. . . For other individuals, no placement outside the institution may ever be appropriate...for these persons, institutional settings are needed and must remain available."*<sup>5</sup>

### **In his concurring opinion, Justice Anthony Kennedy warned about the possibility of tragic consequences for ICF residents if the ADA is misinterpreted:**

*"It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision."*<sup>6</sup>

*"In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting compliance on the cheap, placing marginal patients into integrated settings devoid of the services and attention necessary for their condition."*<sup>7,8</sup>

<sup>1</sup> *Olmstead v. L. C.*, 527 U.S. 581, at 597

<sup>2</sup> *ibid*, at 601-602

<sup>3</sup> *ibid*, at 602

<sup>4</sup> *ibid*, at 607

<sup>5</sup> *ibid*, at 604-605

<sup>6</sup> *ibid* at 610

<sup>7</sup> *ibid* at 610

<sup>8</sup> *(emphasis added on all quotes)*

**Please Oppose the Movement to Eliminate  
Work Centers and 14(c) Wage Certificates for  
Individuals with Intellectual and Developmental Disabilities**

**The Raise the Wage Act:**

**H.R. 582 – Rep. Bobby Scott (D-VA)**

**S. 150 - Sen. Bernie Sanders (D-VT)**

**The Transformation to Competitive Employment Act:**

**H.R. 873 - Rep. Bobby Scott (D-VA)**

**S. 260 – Sen. Bob Casey (D-PA)**

Thousands of individuals with intellectual disabilities enjoy the opportunity to work in a specialized environment that nurtures them and accommodates their mental, physical and behavioral challenges, while rewarding them with specialized wages that, while not equal to full minimum wages, are appropriate to their level of productivity and their capacity to work. These opportunities rely on specialized wage certificates as provided for under Section 14(c) of the Fair Labor Standards Act. The employment usually takes place at facility-based work centers, sometimes referred to as sheltered workshops. These centers provide more than employment. They provide a protected atmosphere suited to the intellectual and behavioral challenges of the individuals who work there. They cater to a higher-needs population, which includes people who may have frequent seizures, who may act out physically, even violently, when stressed, or who may need help toileting or to have their adult diaper changed. This is a specialized environment for a special population.

In the first weeks of the 116th Congress, two bills have been introduced in the House and Senate that would eliminate these employment opportunities for individuals with intellectual disabilities. Proponents of these bills describe them as civil rights issues, asking:

***“If a non-disabled person has the right to work for competitive wages, why should a person with intellectual disabilities be denied the right to work for full, competitive wages?”***

This appears to be a perfectly reasonable question, until you think of the different forms of disability, and the severity of some intellectual disabilities. Then the matter becomes complicated, as not all disabilities are equal. A more accurate question would be:

***“If a non-disabled person has the right to work for competitive wages, why should a person with intellectual disabilities who is capable of working at an equal capacity be denied the right to work for competitive wages? And why should a person who is not capable of working at a competitive capacity be denied the opportunity to perform any work at all?”***

**Why VOR opposes these bills:**

The movement to promote competitive employment for disabled individuals, encompassing people with visual, auditory, and physical disabilities as well as many people with I/DD, is a noble effort, a true civil rights issue that is overdue. As a society, we *should be* creating opportunities for those who want to work, and who are capable of integrating into the mainstream and working at a competitive level. But the implications of these two bills echo the “one-size-fits-all” mentality that dominates the I/DD system and marginalizes those individuals who do not fit into the “one size” population. “One-size-ism” will never be appropriate disability policy. The I/DD population is too complex and diverse to be treated with simplistic, one-sized solutions.

Both of these bills are aimed at providing competitive, integrated employment opportunities for those capable of achieving this level of employment, but they also insist on eliminating the current opportunities provided for those not capable or not desiring this level of employment.

The thinking behind this movement is that work centers are bad things that limit the individual’s capacity, and that given the opportunity to work in a competitive, integrated environment, all individuals will rise to their full capacity. Proponents of this movement, when forced to admit that some people will be shut out or left behind, speak as though this is an “acceptable consequence” of their plan. It is not. These are human lives. These are not disposable, expendable individuals. These people have families who love them and want the best for them.

**There is no reason to accept these “acceptable consequences”, especially when there is no correlation between eliminating 14(c) wage certificates and investing in employment opportunities for individuals with disabilities.**



## Please Support (The Autism CARES Act of 2019)

### The Autism Collaboration, Accountability, Research, Education & Support Act of 2019

These bills [H.R. 1058, introduced by Rep. Chris Smith (R-NJ) and S. 427, introduced in the Senate by Senator Bob Menendez (D-NJ), respectively] would reauthorize the federal autism programs that were last reauthorized by the Autism CARES Act of 2014. These include research and surveillance initiatives at the NIH and CDC, initiatives to raise public awareness and increase early detection of autism, and funding to train health care providers and autism support specialists. The renewal emphasizes the fact that autism does not disappear at adulthood or at any stage of life, and that all of these programs need to account for people with autism across their lifespan.

The renewal would expand the original bill to include further research into the causes, diagnosis, and early and ongoing detection, prevention, and treatment of autism spectrum disorder across the lifespan. The bill also emphasizes a greater commitment to reducing disparities within the autism community by improving access to clinical services for youth and adults from diverse racial, ethnic, geographic, or linguistic backgrounds.

The 2014 bill authorized funding through 2019. The 2019 bill would renew the authorization through 2024. To sign on to H.R. 1078, or for more information, please contact Kelsey Griswold in Representative Chris Smith's office at [kelsey.griswold@mail.house.gov](mailto:kelsey.griswold@mail.house.gov). To sign on to S. 427, or for more information, please contact Stephen Lieberman in Senator Bob Menendez' office, at [stephen\\_lieberman@menendez.senate.gov](mailto:stephen_lieberman@menendez.senate.gov).



**Please Support The HEADs UP Act of 2019**

**The Healthcare Extension and Accessibility for Developmentally Disabled and Underserved Population Act**

This bill, H.R. 2417, introduced by Rep. Seth Moulton (D-MA), would designate people with I/DD as a Medically Underserved Population (MUP), opening access to much needed primary care and specialist services, incentivizing new research, and authorizing more favorable reimbursement rates for providers who treat this population.

People with I/DD meet every criteria to be classified as a MUP: they lack access to primary care services because providers have not been trained to treat them; they experience poverty and infant mortality at higher rates than the non-disabled population; and the I/DD population over 65 is growing rapidly. The only reason that the I/DD population has not been designated as a MUP is because they do not live together in a geographic area.

Designating people with I/DD as a Medically Underserved Population will lead to improved health outcomes, increased longevity, and enhanced quality of life for people with I/DD and will help to fully realize the promise of the Americans with Disabilities Act.

To sign on to this bill or for more information, please contact Olivia Hussey in Representative Seth Moulton's office at [olivia.hussey@mail.house.gov](mailto:olivia.hussey@mail.house.gov).



## The Importance of Medicaid to Our Loved Ones with Intellectual and Developmental Disabilities

Of the 69 million Americans enrolled in Medicaid, some 5 million have I/DD. For them, Medicaid is not an optional program. It is an essential one for them to participate in society and, in many cases, to be safe and healthy. VOR urges the Congress to protect their needs in considering any Medicaid changes.

**Who is VOR and why do we care about Medicaid?** VOR is a national nonprofit organization that advocates for high quality care and human rights of all persons with I/DD. Most of our members are the families of individuals with severe and profound I/DD, many of whom also have significant medical and behavioral problems. Medicaid and Medicaid-approved facilities and services are essential for their health, safety, and happiness.

**How disabled are most VOR family members?** The short answer is *extremely*. Many function at the level of an infant or toddler. Most need assistance in feeding, bathing, diapering, dressing, lifting and the administration of medications and therapies. They depend on staff to attend to seizures, regularly fit orthotic equipment to prevent deformities, address maladaptive behaviors and monitor the environment to prevent them from harming themselves or others, or to protect them from those who would do them harm. Some also require tracheotomies and ventilators to assist in breathing. In short, the people we represent need 24- hour, around-the-clock supervision for their survival.

**How many Americans have severe and profound ID?** About 250,000 people, less than 4% of all people with I/DD and some .36% of all people receiving Medicaid, have severe or profound ID. Any reduction in Medicaid assistance, intended or not, would threaten their lives.

**What about others with I/DD?** Medicaid also serves others with I/DD who, with some assistance, are able to work and be tax-paying members of society. Medicaid funding is a key ingredient in their ability to be productive citizens.

**What does VOR want the Congress to do?** Should the issue of Medicaid cuts, in any form, come up for a vote, we hope you will take no action that threatens the lives of persons with severe and profound I/DD and other significant disabilities or the ability of others with I/DD to make valuable contributions to American society.