



VOR
Main Office
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007
Toll Free: (877) 399-4867
<https://www.vor.net>

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
(646) 387-2267
hdwyer@vor.net

President
Joanne St. Amand
20 Sutton Place
Cranford, NJ 07016
(908) 272-0399
jrst.amand@verizon.net

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. We advocate for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD) and autism. **VOR believes that the best way to meet the individual needs of every member of this diverse population is to ensure that each person’s medical, intellectual, emotional, and behavioral challenges are met, while ensuring that individuals, families, and guardians are able to choose from a full array of options.**

VOR primarily represents individuals with the most severe degrees of I/DD and autism, and their families and guardians. These are individuals whose needs are existential. They become physically full grown, age-wise, yet typically function at an intellectual level ranging from a few months to two or three years. Most have significant physical and/or psychiatric/behavioral issues. They need assistance in feeding, bathing, toileting, diapering, dressing. They depend on staff to lift them, attend to seizures, and prevent them from harming themselves or others.

Because of these complex care needs many of these individuals reside in federally licensed facilities where they can receive the medically needed services and 24/7 support. Unlike some other organizations, VOR supports a variety of quality residential options and services, including own home, family home, community-based service options and Medicaid-licensed intermediate care facilities (ICFs) for individuals with intellectual disabilities.

VOR SUPPORTS:

- Solutions that recognize that for some individuals with I/DD, physical and mental needs must be prioritized over socialization with the non-disabled community and a stable stream of services and residential accommodations must be available for them.
- Protecting individual choice while also allowing families and guardians to make these critical decisions responsibly when the individual lacks the capacity to do so for themselves.
- Updating federal policy to reflect the changing needs of an individual with I/DD. Specifically, this means removal of funding silos between and amongst agencies and programs. These hurdles typically impede and delay medically necessary care.
- VOR appreciates incremental improvements, while urging Congress to enact system-wide reform and modernization of policies to establish a cohesive system of supports for the disabled – particularly for the most vulnerable of this population, those who cannot advocate for themselves.

We look forward to being a resource for you during the 118th Congress and working with you to improve services and support available to our nation’s most vulnerable individuals. If you have any questions regarding VOR’s position on any of the issues we have raised, please reach out to our Executive Director, Hugo Dwyer, at hdwyer@vor.net.



VOR
Main Office
836 S. Arlington Heights Rd. #351
Elk Grove Village, IL 60007
Toll Free: (877) 399-4867
<https://www.vor.net>

Executive Director
Hugo Dwyer
72 Carmine St.
New York, NY 10014
(646) 387-2267
hdwyer@vor.net

President
Joanne St. Amand
20 Sutton Place
Cranford, NJ 07016
(908) 272-0399
jrst.amand@verizon.net

H.R.2941 / S.1332: Recognizing the Role of Direct Support Professionals Act

Senators Maggie Hassan (D-NH) and Susan Collins (R-ME) have introduced similar bills several times in recent years. This year, it passed the Senate by unanimous consent. Rep. Brian Fitzpatrick (R-PA) has introduced a companion bill, **H.R.2941** in the House.

This bipartisan measure would require the Office of Management and Budget to establish a separate category within the Standard Occupational Classification system for the nearly five million direct support professionals (DSPs) who care for people with intellectual disabilities and the aging population. This is an important first step in helping the Congress,, the General Accounting Office, and the Congressional Budget Office understand the nature of this workforce, the need to ensure their safety as well as the safety of those who receive their care, and how to strengthen and support this workforce in the face of a devastating shortage of caregivers that truly threatens the lives of our most vulnerable Americans.

We ask members of the House of Representatives to join together to pass this important bill.

- <https://www.congress.gov/bill/118th-congress/house-bill/2941>
- <https://www.congress.gov/bill/118th-congress/senate-bill/1332>

H.R. 7267 - The Disability Community Act

Representatives Paul Tonko (D-NY) and Brian Fitzpatrick (R-PA) introduced H.R. 7267 to amend Title XIX of the Social Security Act to provide a temporary higher Federal medical assistance percentage (FMAP) for Federal expenditures under the Medicaid program with respect to services furnished in intermediate care facilities and home and community-based services for individuals with intellectual and developmental disabilities (I/DD).

The bill would increase the FMAP to 90% for three years for all states, and cover all individuals with I/DD. We ask members of the House to support this bill. We ask members of the Senate to consider introducing a companion bill. We recognize the cost of increasing the FMAP makes it unlikely that the bill will be passed in this Congress. However, we want to share it with you now so you can best understand what it will take to rebuild our DD System after decades of insufficient funding and begin to consider how best to fund these critical needs.

- <https://www.congress.gov/bill/118th-congress/house-bill/7267>

S.4120 / H.R.7994 - Long-Term Care Workforce Support Act

This is a new bill, recently introduced by Senator Bob Casey (D-PA) and Representative Debbie Dingell (D-MI). VOR supports this bill and is grateful to have been among the organizations who worked with the bill's authors and to have made significant changes in the bill language to ensure that they cover all direct support professionals (DSPs) equally, regardless of setting or Medicaid funding stream.

This bill was drawn from several existing bills that had originally provided funding for HCBS services only. The new bill addresses the needs of the full I/DD, autism, and aging services workforce. They reflect the on-the-ground reality that supporting only part of the workforce would be counterproductive, resulting in the closure of services that for some individuals with the highest levels of need.

The LTCWSA would increase the Federal medical assistance percentage (FMAP) by ten percentage points and provide \$100 billion in a variety of grants to states for additional programs. The bill requires that 85% of the FMAP increase must go to improve compensation, benefits, working conditions and training for the DSP workforce. The bill includes provisions to improve safety protocols for both the caregivers and for those receiving their care.

The goals of the bill are to improve compensation for DSPs, thereby reducing vacancies and turnover, and to ensure that they are treated as health care professionals and receive the respect that they deserve. The bill aims to increase the number of DSPs, including in rural communities, where there are considerable shortages. The bill is also designed to strengthen the workforce in order to support the 53,000,000 unpaid family caregivers who are providing complex services to their loved ones in the home.

The bill requires the Secretary of Health and Human Services (HHS) and the Secretary of Labor to evaluate program effectiveness annually until 2036.

VOR has a difference of opinion on one matter in the bill. The authors of the bill added a provision to make permanent the Money Follows the Person Rebalancing Demonstration Program (MFP). **We believe that this provision should not be included in the bill**, as it has no direct or indirect relation to the DSP workforce shortage. MFP should be judged on its own merits and shortcomings in a separate bill, such as the one recently introduced in the House.

Despite our objections to inclusion of this provision, we are grateful to have had a seat at the table, to have had our voices heard, and to have been part of the effort that resulted in the bill being redrafted to apply to the entire DSP workforce, and thereby all people receiving services through Medicaid LTSS system. We hope to continue to work with the sponsors of this bill to improve the next version of this bill in the 119th Congress.

- <https://www.congress.gov/bill/118th-congress/senate-bill/4120>
- <https://www.congress.gov/bill/118th-congress/house-bill/7994>

VOR's Objections to The Permanent Reauthorization of the Money Follows the Person Rebalancing Demonstration Program (MFP)

Representative Debbie Dingell (D-MI) recently introduced H.R.8109 which would make MFP permanent. **We ask Members of Congress not to pass any such legislation without thoroughly examining the program and addressing its shortcomings.**

MFP was originally established as a 5-year, \$1.4 billion Demonstration Program in 2005. Reauthorizations and reappropriations have, unfortunately, occurred every few years without any review or assessment. Here is why VOR believes it should not pass without substantial modifications to reflect the radical change in conditions since the original legislation.

MFP has helped many people move into settings better suited to their needs. But it has also hurt many high-needs individuals as it has often resulted in the closure of intermediate care facilities (ICFs).

ICFs offer higher levels of care than is available in Home- and Community-Based Services (HCBS) settings. They are often medically necessary for people with the most severe and profound intellectual disabilities and autism. Under MFP, when a person leaves an ICF, funding for their care moves from one Medicaid funding stream (ICFs) into another, HCBS. Subsequently, ICF placement is rarely made available to anyone who has requested ICF care. This has resulted in the erosion of the ICF system and fewer available placements for those who choose ICF care. Absent these ICF beds, individuals and their families are struggling to find appropriate and quality residential care.

Hearings are needed to modernize the program. Billed as a "rebalancing" program between ICF and HCBS placements, the vast majority of funds has long since moved from funding people in ICFs to funding them in HCBSs. Making MFP funding permanent in its present form would deny thousands of people with severe and profound intellectual disabilities and autism the ability to receive the care they need. What is the proper balance between systems today?

Hearing from all stakeholders – including those seeking ICF care – is critical prior to making permanent a program that reduces funds for a residential care option.

Further, a GAO study of this and other issues regarding the implementation of the MFP program and a CBO score to determine future costs would provide important information about the shape and future cost of the program.

We respectfully ask the committees of jurisdiction to hold hearings to examine the MFP program rather than simply making it permanent.

- <https://www.congress.gov/bill/118th-congress/house-bill/8109>

VOR Advocates for Necessary & Significant Changes to The Autism CARES Act Prior to Reauthorization

Many of VOR's members care for family members with severe or profound autism – a portion of the autism community that finds itself overlooked throughout autism research and policy. VOR shares the concerns of the Autism Science Foundation (ASF) that the Autism Collaboration, Accountability, Research, Education, and Support (CARES) Act (*H.R.7213*) requires significant changes for the legislation to best address pervasive gaps in research and reflect lived lessons and current science that has evolved since the last reauthorization.

To that end, ASF has proposed reforms to the Autism CARES Act, which VOR wholeheartedly supports.

- The creation of a new National Institutes of Health (NIH) entity: the Office of Autism Research (OAR)
- The elimination of the Interagency Autism Coordinating Committee (IACC), which has failed to acknowledge the distinct needs of families of individuals with profound or severe autism.
- Direct the Health Resources and Services Administration (HRSA) to include the development of a special patient standard of care for persons with profound or severe autism.
- Establish demonstration grant programs to assist states with service provision and to provide services for adults with autism.
- Authorize a GAO study on the financing of autism treatments and services: including housing needs, current public and private insurance coverage for autism.

These are bold and *necessary* steps towards improving the lives of individuals with severe and profound autism. VOR urges you to support these efforts to update and improve the Autism CARES Act to ensure future research will move the needle forward in addressing the rising number of autistic individuals and garnering insights into best practice approaches for meeting their numerous medical care needs.

Core to VOR's mission is to promote and protect choice for individuals with I/DD and autism and their families. They need research and data to make informed choices. Currently, we do not have these data because the needs of those who cannot self-advocate are being left out. Supporting these legislative changes will help our families make the informed choices that are right for them.

- <https://www.congress.gov/bill/118th-congress/house-bill/7213>

We look forward to working alongside Members of Congress on behalf of our community. If you have any questions regarding VOR's position on any of the issues we have raise, please reach out to our Executive Director, Hugo Dwyer, at hdwyer@vor.net.