

House Energy and Commerce Committee Republicans

Re: Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion

Dear Leader Cathy McMorris Rodgers and Members of the House Energy and Commerce Committee Republicans:

Thank you for the opportunity to contribute comments to the forum regarding the House E&C Republicans' platform, as stated in "Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion." The document clearly recognizes many of the unmet needs of people with intellectual and developmental disabilities (I/DD) and autism, and offers several constructive solutions. We do have a few suggestions for improvements, along with some personal stories and other materials, but first, let us introduce ourselves.

VOR - A Voice of Reason was founded in 1983 by families of individuals with severe I/DD. For nearly forty years, we have advocated for high quality care and human rights for **all** people with I/DD, behavioral disabilities, complex medical conditions, and autism. VOR stands apart from organizations that believe inclusion is the only acceptable path. We take a broader view, recognizing the diversity of the I/DD population and advocating for a wide range of residential and employment options in order to meet both their aspirations and their needs. VOR supports the aspirations of those with less significant physical and intellectual challenges who wish to be included in the community, while steadfastly advocating on behalf of those who are so critically impacted with intellectual, medical, physical, or behavioral disabilities that attending to their existential needs must be the primary focus of their families and caregivers. For these individuals, we believe that the family or legal guardians – not professional advocates – should determine what is best for their loved ones.

We will submit suggestions for the policy document in the order the recommendations appear in the document, **along with some supplementary articles and personal stories to amplify our message**. First, however, we would like to identify one other item currently impacting the disability population: The critical shortage of Direct Support Professionals (DSPs) threatens to upend every sector of our long-term care systems. We have built a system that relies on an underpaid and undervalued workforce and it is in danger of falling apart.¹

Access to Long-Term Services and Supports

The experience of many of VOR's families is consistent with the report's conclusion that our system of long-term services and supports (LTSS) needs to become much more accessible. However, based on our first-hand understanding of just how severe these disabilities can be, we believe that the system must be as expansive as possible to reflect that reality, and its improvement not limited to more accessibility for Home and Community Based Services (HCBS) only. The unique and varied needs of this population call for a diverse set of residential and treatment options, ranging from supports in one's own home or family

¹ ***'People will die waiting': America's system for the disabled is nearing collapse*** – Dan Goldberg, Politico, Aug. 10, 2022
<https://www.politico.com/news/2022/08/10/americas-system-for-the-disabled-is-nearing-collapse-00050713>

home to intentional communities, group homes, farmsteads, ICFs,² and other options.

In the previous paragraph, we noted the need for ICFs, more formally known as Intermediate Care Facilities for Individuals with Intellectual Disabilities or ICFs/IID. While not appropriate for most people with I/DD, ICFs have proven to be a good setting for many people who will have extraordinary needs for their whole lives. Tragically, the nature of some I/DD syndromes is such that these individuals will never reach a functioning level beyond that of an infant and/or have severe lifelong behavioral and/or medical issues. That is the case for a small number of individuals with I/DD. We cannot wish away their needs; they are a lifelong reality. For those individuals, ICFs are an important part of our LTSS system, a critical component of a full continuum of care.

ICFs are no family's first choice. Everyone wants their loved one to receive the best care possible, if not in their family home, then in the least restrictive setting. When the needs of their loved one are not being met in one setting, they try to find another least restrictive placement. This usually involves several attempts to find an appropriate setting in a group home. It's only after they determine that the HCBS system does not offer the care they need, or after the local providers refuse to accept the individuals into their homes (either because the reimbursement levels are too low to provide the needed services or because the group homes lack the resources to meet the care needs of the individuals), that they look to an ICF as a solution. ICFs are the last best hope for many. For some individuals with I/DD, an ICF is the least restrictive environment. As the Supreme Court said in *Olmstead*, quoting VOR's amicus brief, "*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.*"³

The needs of individuals with I/DD change as they grow through childhood, teenage years, early adulthood, and beyond. Early childhood presents one set of challenges, while certain behavioral problems may arise in the early teens through mid-late twenties. People may settle in well in one environment -- say a small group home -- then as they age that home may not be able to handle their needs. People with Down syndrome often experience early-onset dementia in their forties or fifties, and find they need a different setting more appropriate to their needs than the home where they had previously thrived. We need a system that is flexible and comprehensive to accommodate both immediate and long-term needs as well as the normal life-changes that every individual experiences. We need a system that offers all people with I/DD and autism ready access to a full array of services.

VOR would like to address one particular part of this report and clarify some of the language used by this committee. On page 6, there is mention of an "institutional bias,"⁴ a term often used by advocates, advocacy organizations, and others as denoting a bias toward ICFs. Most families who have applied for placement in an ICF would argue that the opposite is true. Many states closed their state-operated ICFs to new admissions years ago in an effort to phase them out. Some states have eliminated them entirely, leaving only a few private providers who offer ICF-level care but rarely have placements available. When people are not accommodated by the HCBS system, this "anti-institutional bias" can result in people being sent to psychiatric hospitals, nursing homes, or forensic facilities, none of which are appropriate

² Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF, or ICF/IID) are larger congregate care facilities designed to meet the higher needs of individuals with severe/profound I/DD and autism, many of whom also have complex medical and behavioral conditions. Larger congregate care facilities rely on an economy of scale to provide residents with 24/7 nursing and doctors on the premises or on call, and often provide on-campus services including dental, and psychiatric, physical therapy and behavioral therapy. ICFs are funded through Medicaid, though separate from the payment silo that provides for Home and Community Based Services.

³ *Olmstead v L.C.* 527 U.S. 58, p. 605 <http://supreme.justia.com/cases/federal/us/527/581/case.html>

⁴ Medicaid, however, only requires coverage of long-term care in nursing homes and other institutional settings. HCBS care remains an optional service for states (this is commonly referred to as Medicaid's "institutional bias"). House Energy and Commerce Republicans' Disability Policies in the 21st Century: Building Opportunities for Work and Inclusion - p.6

settings for people with severe and profound I/DD. We believe that the erosion of the ICF system has led to bad outcomes for many individuals.

The movement away from ICF care is reflected in Medicaid payments. Looking only at long-term funding of programs for people with I/DD, not at the total long-term funding that is dominated by nursing home care, the vast majority of federal dollars now goes to HCBS residences, not to ICF residences. In the early 1980s, before the creation of the HCBS program, almost all federal dollars went to ICFs. In sharp contrast, more than three-quarters of federal dollars now go to HCBS funding. The institutional bias that existed before the government started funding the HCBS program has long since disappeared. It remains solely as a talking point for the ideological opponents of ICF care.

We agree with the House Energy and Commerce Republican report that there should be better access to HCBS settings, and that there should be no “institutional bias.” But we believe that there is now an “anti-institutional bias” in both policy and appropriations that is harmful to the population that needs ICF care. As many in VOR’s community repeatedly face hurdles in securing treatment and care settings that work best for their care and care setting needs, we will speak to that here.

Recent legislation has not only favored HCBS settings, it has entirely excluded funding for people receiving Medicaid long-term care in non-HCBS settings, such as ICFs and Skilled Nursing Facilities (SNFs). The American Rescue Plan Act (ARPA), for example, was supposed to alleviate some of the effects of the first wave of the Covid-19 pandemic, and provided a 10-percentage point increase in the FMAP (the amount paid by the federal government to states for LTSS services under Medicaid) only for HCBS services. Clearly, everyone with I/DD suffered the effects of the pandemic, no matter what type of setting they resided in or which of Medicaid’s funding streams paid for their care. Yet, Congress’ actions only addressed funding for the HCBS portion of the disability population. We strongly believe there is a need for greater appropriations for people with I/DD in future spending bills; we hope that Congress will ensure that it goes to all recipients of LTSS services, not only to people in one type of setting.

The same anti-institutional bias continued into the Better Care Better Jobs Act and then into the original House version of the Build Back Better Act, where \$400 billion was requested for HCBS services only. Again, VOR and other groups requested parity, a fair share of the funding based on the most recent year’s ratio of HCBS to ICF payments for people with I/DD (roughly 90% to 10%).⁵ As you know, the bill and this provision never became law. While we strongly believe there is a need for greater appropriations for people with I/DD in future spending bills, we hope that Congress will ensure that it goes to all recipients of LTSS services, not only to people in one type of setting.

Bias hurts. Everyone should have access to the services that best suit them, unimpeded by any laws or government agencies imposing either an institutional or an anti-institutional bias. We support the Energy and Commerce Republicans’ call for access to HCBS services. However, we think the best policy is not to focus on just one of many available options. Moving forward, the committee has the opportunity to legislate from a perspective of providing the necessary funding for a full range of residential options so individuals with I/DD can choose to live in the setting they believe will best meet their care needs and provide the best quality of life.

⁵ <https://www.kff.org/medicaid/state-indicator/spending-on-long-term-care/?dataView=0¤tTimeframe=0&selectedDistributions=icf-id--home-health-and-personal-care&sortModel=%7B%22collId%22:%22Location%22,%22sort%22:%22asc%22%7D>

Accommodations in the Community

Access to LTSS Through Family Caregiving

VOR supports family caregivers whenever and however possible. This is especially true for families with loved ones with I/DD, as this can, and usually does, become a lifelong commitment. At the same time as we face a shortage of DSPs, families that have wanted to care for their loved ones at home are being forced to make a choice between leaving their jobs or placing their family member into a residential facility, if they can find one that meets their needs. It would be far preferable for all concerned for the government to pay family caregivers to provide the services of the DSP.

We recognize that some people may object to the government paying people to be parents. However, these are extraordinary circumstances and parents can be the *best* caregivers, especially when provided with the proper supports and training. In Oregon, for example, during the Covid-19 pandemic, there was a temporary measure that paid parents to leave their jobs and take care of their family members because no DSPs were available. VOR wrote a letter on behalf of parents who requested that the program be extended, due to its success in providing care as well as the fact that they were still faced with a shortage of DSPs.⁶

We support creation of a nationwide program like this. Eligibility requirements would have to be established, of course, depending on the severity of disability, number of hours of care to be covered by CMS, life expectancy of the individual or the caregiver, availability of DSPs in the area, and a host of other determinants. But if done correctly, the overall effect could be cost savings to the Medicaid system, better care for people who need DSPs, some relief to the shortages of DSPs, and support for families in need. We would encourage the E&C Republicans to look further into the possibilities that such a program might offer.

Barriers to Integrated Employment

VOR unconditionally supports programs that create opportunities for competitive, integrated employment (CIE) for people with I/DD who are capable of performing 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 reduced wages to a defined group of individuals with I/DD whose functioning level does not permit them to perform the work that employers require to pay marketplace wages. Section 14(c) enables these individuals to appreciate the dignity and obtain the benefits of work while providing useful services to the businesses that participate in CIE.

The elimination of sheltered workshops is contrary to the aims of *Olmstead* and is wholly unnecessary to avoiding discrimination in employment services. *Olmstead* recognizes that states must maintain a range of services - some necessarily more restrictive than others - to care for a diverse population of individuals with disabilities.⁷

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. It requires employers to make special accommodations for their

⁶ This letter is included in the package of supplementary materials, and is available for download at https://www.vor.net/images/stories/2021-2022/VOR_Letter_Supporting_Parent_Caregivers_in_Oregon.pdf

⁷ J. Gardner Armsby, *The War on Sheltered Workshops: Will ADA Title II Discrimination Lawsuits Terminate an Employment Option for Adults with Disabilities*, 31 Ga. St. U. L. Rev. (2015). at 27. <https://readingroom.law.gsu.edu/gsulr/vol31/iss2/6>

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 are able to earn wages that are commensurate with their level of productivity and their capacity to work. 14(c) programs are carefully regulated by the Wage and Hour division of the U.S. Department of Labor. No one is forced to participate in these programs. The application process is time-consuming, and must be reviewed every two years. Applicants are repeatedly tested 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.

The individuals who are covered by 14(c) certificates are people who could not reasonably be accommodated in most conventional work environments. Some have medical conditions, including occasional or frequent seizures. Others have behavioral disorders and are prone to self-injurious or aggressive behaviors, often resulting in violent outbursts. Still others require help toileting or having someone change their adult diapers. 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. The centers provide job coaches to help them develop their skills, who have also been trained to handle their physical, medical, and behavioral challenges as they arise. 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.

These vocational centers and commensurate wage programs provide more than employment. They afford workers opportunities to build self-esteem, develop friendships, and engage in their communities. People who work at these centers do so without fear of being fired, or of having to live up to competitive standards of productivity they cannot meet in order to show their worth. Earned wages, though appreciated, are not the substantive reward for these individuals.

VOR asks Congress to expand, not decrease, the range of employment opportunities in order to accommodate a broad range of people with I/DD. This is not an either/or situation. Congress can help those who choose to participate in a competitive environment without depriving others, who cannot, of opportunities to work. VOR supports paying minimum wage or better to people with I/DD who are able to work in the competitive workplace. However, ignoring the reality of different degrees of disability would result in thousands who cannot perform competitive work losing their jobs. Such an outcome would be yet another tragic result of a policy advocated by groups with an ideology that does not reflect the full spectrum of the I/DD community. The answer to meeting the work needs of the wide range of individuals with I/DD is simple: Pay minimum wage to people with I/DD who can, with reasonable accommodations, perform at a competitive productivity level, and continue the section 14(c) program for those who cannot.

The DSP Crisis

There is a severe shortage of Direct Support Professionals that is affecting all services provided to the intellectually disabled, physically disabled, aging, and autism communities. If the shortage continues, it will overwhelm every program mentioned in the Energy and Commerce Republicans' Report.

We cannot overemphasize the need for Congress to prioritize this matter. It has been growing for years, brought about by a system that has relied on a failed business model of hiring underpaid and undervalued workers and, despite astonishingly high turnover rates, continuing to replace them and train new employees instead of retraining those in whom they had already made a substantial investment. The

President's Committee for People with Intellectual Disabilities issued a report in 2017⁸ that clearly illustrated the problem, but nothing has been done to address it. The Covid-19 pandemic made it far worse, and even as the rest of the nation returns to work, the shortage of DSPs just gets worse. Few people want these jobs, especially when less demanding entry-level positions at fast-food restaurants and big-box stores pay higher wages. Now we are faced with a network of I/DD service providers who are unable to sustain their workforce.

The shortage is forcing providers to shutter group homes or not open new ones. In Minnesota, for example, at one point, the National Guard had to be called in to administer to I/DD clients in facilities that were unable to find workers to attend to the residents. Facilities in other states have closed, residents are being sent home, and families are having difficulties finding new placements for their loved ones. Some people have been sent to unsuitable institutional facilities like nursing homes or psychiatric wards for lack of a better alternative.

There is a simple, effective way forward. It will cost money but, without it, programs to expand community services of any kind will fail for want of staff. The answer will combine improving wages and training for the *entire* DSP workforce. To pay workers in only one sector, such as elder care or group homes or in-home care workers, would devastate the DSP workforce in other sectors. That's not a solution, it's just another predictable disaster. To be effective, the congressional response needs to meet the needs of all DSPs wherever they work.

Wages for DSPs are generally paid through Medicaid and Medicare and administered by CMS. They are therefore tied to the federal minimum wage, which is lower than the minimum wage in most states. Many state governments supplement these wages, but even then, they remain lower than what Target, Walmart, Amazon, or McDonald's is willing to pay. Moreover, new DSP workers are paid at roughly the same rate as employees with five or more years of experience. Until this workforce is compensated in accordance with the demands of the job, the crisis will continue unabated.

The problem can be addressed through a two-step process. The first step would be to have the Office of Management and Budget define a classification for Direct Support Professionals that recognizes them as a distinct class of health care professionals and describes a set of duties that characterize the workers in this class and the training that would be required for entry level positions as well as career advancement.

Second, once a DSP classification is created, the Center for Medicare and Medicaid Services could establish a special wage scale that would be appropriate for this new class. The DSP scale would need to be higher than the minimum wage in each state to encourage people to choose to this profession over the alternatives mentioned above.

VOR urges Energy and Commerce Republicans to prioritize this issue, and find solutions to end the crisis and stabilize the industry that is the backbone of the system of I/DD LTSS. A solution is essential to fulfill the objective of expanding living and work arrangements for people with I/DD.

⁸ *America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy* – President's Committee for People with Intellectual Disabilities, Report to President Trump, 2017
https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

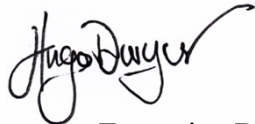
Conclusion

The number of babies born with various forms of I/DD and severe autism continues to grow. People with I/DD are living longer. Their needs generally increase as they age. It is important to act quickly and decisively. Our present system is broken. It is fragmented and underfunded.

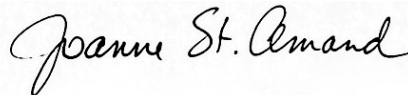
To make such a system – or any reform – work, Congress must also address the DSP labor shortage. Without adequately trained and paid staff, people with I/DD will remain underserved and vulnerable.

VOR is highly appreciative of all the work that the House Energy and Commerce Committee Republicans have put into creating this policy statement and for welcoming public comments. Our suggestions for improvement are the product of the day-to-day experience of our members. They are designed to broaden the scope of your policy proposals to serve all people according to their needs and desires in the places and manners in which they choose to live and work.

We look forward to working with you to create a better future for all people with I/DD.



Hugo Dwyer – Executive Director



Joanne St. Amand – President

Supplementary Materials:

The DSP Crisis:

- ***‘People Will Die Waiting’: America’s System for the Disabled is Nearing Collapse***
by Dan Goldberg, POLITICO, August 10, 2022

Access to Long-Term Services and Supports:

- ***Marjorie’s Story, Why We Choose Murray Center***
by Peggy Strong, VOR Voice, December, 2016
(A Video of Marjorie’s Story and other Murray Center Success Stories are available at <https://www.youtube.com/playlist?list=PLdENLQViurXAEynLtW7sU0ysYZk2Cdy0>)
- ***No Good Options – The Forced Closure of Glenwood Resource Center***
by Sybil Finken, submitted for testimony August 16, 2022
- ***A Voice for Joshua***
by Vance Goforth, VOR Voice, December, 2021
- ***Olmstead – Essential Passages Protecting Choice***
by VOR’s Legislative Committee, revised August, 2022

Accommodations In the Community – Access to LTSS Through Family Caregiving

- ***VOR Letter Supporting Family Caregivers in Oregon***
by VOR’s Legislative Committee, June 1, 2022

Accommodations In the Community – Barriers to Employment

- ***My Daughter Laura, and the Benefits of 14(c) Programs,***
by Dawn Kovakovich, submitted for testimony August 15, 2022
- ***Matthew’s Story – An Existential Threat Against the Significantly Disabled***
by Harris Capps, VOR Voice, December, 2019
- ***Myths and Facts about Vocational Centers and 14(c)***
by VOR’s Issues and Oversight Committee, revised June, 2022

All supplementary materials are available to download and print at <https://www.vor.net/legislative-voice/advocacy-letters/item/vor-comments-to-house-energy-commerce-committee-republicans>