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VOR Legislative Initiative - May, 2022

Dear Members of the U.S Senate, the U.S House of Representatives, and Congressional Staff,

We would like to introduce you to VOR - A Voice of Reason. We are a national non-profit organization founded in 1983. VOR is a true grass-roots organization, consisting mostly of families of individuals with significant intellectual and developmental disabilities (I/DD) and autism, often complicated by medical, psychological, and/or behavioral conditions. Many of these individuals have extraordinary needs, and receive specialized treatment and care living in intermediate care facilities for individuals with intellectual disabilities (ICF/IID or ICFs). Others receive services living in smaller group homes or in their family home. The common thread here is that we represent people at every level of disability whose families feel that their needs are not being met by federal programs, or who fear that the programs that their loved ones rely upon are in jeopardy. VOR advocates for a full continuum of residential care services and employment opportunities in order to meet the needs and aspirations of all of the individuals who make up the diverse population of I/DD. We believe that a full range of options must be supported in order to ensure that families are able to make informed choices in determining what is best for each individual as they pass through the different stages of their lives.

We would like to introduce you to our loved ones, our family members with I/DD and autism. Chances are good that you have seen people in your community who have intellectual and developmental disabilities. Perhaps a neighbor has a child with Down syndrome. Maybe you've spoken with someone with an intellectual disability who works at a local coffee shop or supermarket. You may have seen a television program about the challenges a group of people with intellectual disabilities faces in trying to integrate into their community, or a show about how someone with autism uses it as a superpower to solve complex problems. But these are not the people we are here to talk about today. We want you to know about the many people with I/DD who mostly remain unseen, the high-needs individuals whose disabilities are far more severe. These are truly our most vulnerable Americans, and they need your support.

We ask you to support a full range of residential options. Individuals at one end of the I/DD spectrum have aspirations. They wish to integrate with the general public, to interact with non-disabled individuals and be part of the greater community. For individuals at the other end of the spectrum, basic needs are paramount. They rely on trained professionals to provide a safe environment and access to medical care, psychiatric services, physical and behavioral therapy, and daily assistance with eating, exercise, hygiene, and toileting. It can be argued that in recent years, more attention, and increased government support, has been given to the aspirations of the people at the higher end of the spectrum to the detriment of those with the most significant essential needs.

We ask you to support a full range of employment options, including programs to create competitive, integrated employment as well as employment opportunities that pay commensurate wages for people unlikely to be accommodated in competitive employment settings.

We also ask you to support the *entire* workforce of Direct Support Professionals (DSPs) who serve out family members with I/DD and autism in all settings, regardless of the type of setting or the facility in which they work.

Please read on for more about these issues.



I. Seeking Parity by Increasing Federal Funding for All Forms of Residential Treatment and Care

The Center for Medicare and Medicaid Services (CMS) has two separate funding streams for Long-Term Services and Supports (LTSS) provided to people with intellectual disabilities (I/DD). The stream currently receiving the most funding provides for Home and Community-Based Services (HCBS), supporting most of the people with I/DD who live in group homes, at home with family caregivers, or semi-independently in their own homes or intentional communities. These funds are overseen by the Administration for Community Living (ACL), a powerful agency within the Department of Health and Human Services that controls most of the services provided for the I/DD and Aging populations. The other stream of Medicaid approved long-term services covers non-HCBS care. This includes intermediate care facilities (ICFs), skilled nursing facilities, (SNFs), most nursing homes, and many assisted living facilities. While the individuals who receive services from these two separate funding streams deserve to be given equal consideration, that has not been the case in recent years.

VOR supports all forms of Medicaid-certified residential care. While HCBS settings are often well-suited to the needs of many with I/DD and autism, ICFs are an important component of a full continuum of care. Though not the right fit for most individuals with I/DD, they are often the appropriate residential treatment choice for people with the most significant intellectual disabilities, especially those with co-existing chronic medical conditions, psychiatric complications, and/or behavioral disorders. For some individuals, ICFs provide a stable environment of high-quality care over a lifetime. Other individuals may benefit from ICF care at different stages of their lives, including the teen/early adulthood years or later in life as medical complications compound intellectual disabilities. Unfortunately, the ICF system has been gradually dismantled over the past forty years. Many states have abandoned their state-operated ICFs. Private ICFs have struggled to survive against the “one size fits all” ideology that favors HCBS. We request you support and reinvest in the ICF component of our system. It is the most comprehensive program offered by CMS.

The American Rescue Plan Act (ARPA) was enacted in March of 2021 to cover financial losses that states, federal programs, and different industries had suffered under the first year of the COVID-19 pandemic. In most aspects, ARPA was written to provide equitable funding across the board. In education, for example, it was originally written to provide for public schools only, but was later amended to include private schools, parochial schools, and charter schools, because the students in each of these different types of schools had suffered equally under the pandemic. With DD services, however, ARPA awarded an FMAP increase (the percentage of assistance the federal government provides to states to cover Medicaid costs) of 10 percentage points **to HCBS only**. No equivalent FMAP increase was given to people in non-HCBS facilities, despite the fact that individuals in all LTSS Medicaid services suffered equally under the pandemic. Since then, states have been using their ARPA funds to help improve services only for people in the I/DD or aging populations under HCBS programs.

Unfortunately, both the Better Care Better Jobs Act (BCBJ) and Build Back Better Act included funding solely for HCBS which would have furthered the divide between HCBS and ICFs. While there were Members of Congress working to include parity in funding for ICFs, discussions on this ended as negotiations for a final overall bill once again stalled. VOR wants to ensure that congressional staff and members are acutely aware of this funding gap and its impact on patient freedom of choice and quality of care available at ICFs. The most vulnerable of individuals need federal funding to reflect their complex and diverse care needs – which requires ICFs to receive adequate funding alongside HCBS.

We ask you to please increase funding for the entire system of care for the I/DD and aging communities, regardless of settings, and that you insist on parity for all Medicaid-approved forms of treatment and care.



II. Seeking Parity for Increasing Wages and Training for All Direct Support Professionals

As you know, there is a critical shortage of direct support professionals (DSPs), the caregivers who see to the daily needs of the disability and aging communities. Facilities of all types have been closing in recent months due to inability to hire staff. Low wages, lack of benefits, insufficient training, and no career path all factor into this crisis. However, many DSPs consider being a caregiver to be more than just a job. It is a calling. It is a special type of person who chooses to care for those who cannot care for themselves. This is a demanding job that requires an incredible amount of devotion and personal sacrifice.

Many DSPs receive such low wages that they have to hold two or three jobs to make ends meet. They deserve better. They deserve a more than just a living wage. They deserve a good wage, commensurate with the care they provide. They deserve better training with an established career path that allows them to grow in their profession and help train others. They deserve respect. They deserve our support.

Congress has the power to address this crisis nationally, and to provide for these dedicated workers.

Because the federal government oversees Medicaid services and costs through CMS, wages for DSPs are tied to the federal minimum wage. Many states have set a higher minimum wage, but that does not apply to those whose pay is determined by the federal minimum. Many of the states with higher minimum wages do have provisions to compensate for DSP wages, bringing them to state minimums, but this is still not enough to compete with fast food chains or companies like Target, Walmart, or Amazon, which require no experience and are able to increase wages in order to ensure their facilities are fully staffed.

The Build Back Better Act and the Better Care Better Jobs Act both contain provisions to increase wages and training for DSPs in HCBS settings only. This creates an inequity that would decimate the workforce serving individuals receiving supports in ICFs, nursing homes, and other non-HCBS facilities, as all of these providers draw from the same pool of workers. Who would take a job, or stay in a job, at an ICF if they could get better pay and training doing the same work in a group home down the street? Whether or not this was a deliberate maneuver by the authors of these bills, intended to starve ICFs and nursing homes of their DSP workforce, the fact remains that this concern has been pointed out to them and they have still not amended the bills accordingly.

We ask that **all** DSPs receive a wage commensurate to the services they perform, and have training and career paths that will encourage them to prosper in this field. And, critical to the survival of all forms of care for people in the disability and aging communities, we ask for parity - equal increases in wages and training for **all** DSPs, regardless of the type of facility in which they serve, regardless of which Medicaid LTSS funding stream oversees their pay. We should all care about the individuals they serve, not about the facility in which they provide their services.



III. Please Support All Employment Opportunities for Individuals with I/DD and Autism

VOR supports choice. To provide families with choices, we must support a full array of optional services and programs for all people with intellectual and developmental disabilities (I/DD) and autism. This principle applies to employment opportunities as well as residential services.

While we heartily support programs that will increase opportunities for people with disabilities to participate in competitive, integrated employment, we are concerned that many of the proponents of these programs insist that we eliminate, or phase out, other options. We oppose this particular ideology.

Section 14(c) of the Fair Labor Standards Act 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 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 commensurate wages that are appropriate to their level of productivity and their capacity to work. 14(c) programs are highly 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, they would lose any opportunity to work.

The individuals who are covered by 14(c) certificates are people who would not be well 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. They thrive by having the opportunity to use and improve those skills.

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 in order to show their worth. Earned wages, though appreciated, are not the substantive reward for these individuals.

There have been several bills entered in the 117th Congress that would eliminate programs that offer specialized wages under Section 14(c). The Raise the Wage Act, while dealing with the issue of minimum wage, had provisions in it to phase out 14(c) programs. The Transformation to Competitive Employment Act, while creating opportunities for competitive, integrated employment, would also have eliminated 14(c) options. The Build Back Better Act include grants to states to help create competitive, integrated employment, but required that states eliminate 14(c) programs in order to qualify for the grants. We strongly oppose this type of heavy-handed legislation that favors some people at the expense of others.

We ask that Congress expand, not decrease, employment opportunities for all people with I/DD. This is not a binary, either/or, situation. Congress can help those who choose to participate in a competitive environment without depriving others 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 losing their jobs. This must not be the outcome. The answer 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.



IV. Please Request Studies from the General Accounting Office (GAO)

We are asking Members of Congress to help improve the services offered to people with intellectual and developmental disabilities (I/DD) and autism by requesting formal studies from the General Accounting Office.

1. We would like for the GAO to conduct a comprehensive cost comparison between Intermediate Care Facilities and Home and Community Based Services (including SSI and other supplementary programs) to determine the true costs to taxpayers when all services and supports have been accounted for. What is the full breakdown of federal costs for beneficiaries? Are equivalent services available in both settings, and if not, which services are missing, and what would it cost to provide them?
2. Often, I/DD individuals or their families or guardians sign a waiver to give up their right to Intermediate Care Facility placement. Should the individual's health, medical needs, or preference change, is there a process available for admission to an ICF? If so, does it vary by state? For these individuals, what is the average wait time for an ICF?
3. For individuals who do not sign a waiver but wish to access Intermediate Care Facility services and residency, what is the average wait time? For those who leave an Intermediate Care Facility but find after the 30-day window that Home and Community Based Services do not adequately meet for their needs or their needs change, what is the average wait time to return to an ICF?
4. We would like to request comprehensive mortality data in states that are closing their state-operated ICFs, to help understand the consequences of these closures. Currently, Pennsylvania is in the process of closing the White Haven and Polk State Centers, and Iowa is about to start closing its facility at the Glenwood Resource Center.