



*~ Seasons Greetings from VOR ~
Happy Holidays to all of our Families and Friends!*

*We would like to thank all our members, past and present,
as we celebrate
VOR's 40th Anniversary in 2023!*



As you know, VOR is a national grass roots organization that advocates for the highest quality care, human rights, and for families to have **real choices** in residential options for individuals with I/DD and autism. People investing in VOR through membership dues and donations enjoy the intangible benefits of supporting the very first national organization to advocate for the right of individuals and their families to choose from a full range of residential options, including one's own home, in-home, community-based, facility-based private or state-run facilities. VOR also supports a full array of employment opportunities, as suited to individuals' skills and their choice of settings in which to work.

Since 1983, we have depended completely on the generosity of our members and supporters to fund VOR. Some years have been much more challenging than others. Unfortunately, this is one of those years. Our family members with severe and profound intellectual and developmental disabilities (I/DD), and autism represent only about 5% of the entire population with I/DD and autism. We are the minority of the minority and must work very hard to be heard, and even harder to actually effect policy that will benefit our loved ones.

If we do not speak up for them, who will? Every member is important, and every gift really does count. We are grateful to you for all your years of support to VOR. If you have the means, we again must ask that as you plan your year-end charitable giving, you will please consider a gift to VOR.

Several members have asked about how they can participate in forms of planned giving. As always, we recommend that you contact your tax professional or account administrators to determine which type of contribution is right for you, and to ensure that your donation follows the protocols established by the IRS so that you can maximize your taxable credit.

We would like to remind our members that there are many ways to contribute to VOR, not only through financial donations. One of the most important ways is to give of your time and talents, especially your website and multi-media skills. You can share your story with us, for the Voice or for our website, or share news articles about issues affecting our loved ones for our weekly newsletter. you can follow us on Facebook, and come to our networking meetings. Most of all, we encourage you to share your story with your state legislators, tell them your concerns, and ask them to visit your loved one in his or her home to better understand their lives and their needs.

We are deeply grateful for all your gifts, and for your ongoing support of our mission, our families, and our loved ones with I/DD and autism.

We wish you all the happiest of holidays,

Joanne and Hugo

Joanne St. Amand
Joanne St. Amand

President, VOR Board of Directors

Hugo Dwyer

Hugo Dwyer,

Executive Director of VOR – A Voice of Reason

VOR's January Networking Meeting – A Look at the 118th Congress

January 24, 2023

4 pm Eastern, 3 pm Central, 2 pm Mountain, 1 pm Pacific

Come join us on Zoom for our first networking meeting of the new year.

The meeting will be moderated by Roslyn Leehey and feature a presentation by Gayle Gerdes on the new congress.

Review of the 117th Congress, and Legislation Affecting People with I/DD and Autism

Several bills that would affect the lives of people with I/DD and autism were introduced in the House and Senate in the 117th Congress, but few actually passed into law. The most significant bill to have passed was the American Rescue Plan Act (ARPA), which was intended to provide funding to mitigate the financial losses suffered by businesses, educational services, non-profit organizations as a result of the first year of the COVID-10 pandemic. The most significant bill that failed to pass was the Build Back Better Act, which encompassed many of the Biden Administration's political and economic objectives. Other bills that failed to pass included an effort to recognize Direct Support Professionals, two bills that would have phased out/eliminated sheltered workshops, and a bill designed to phase out/eliminate Intermediate Care Facilities.

References to Democrats and Republicans are not meant to imply that VOR endorses or opposes either one. They merely state the numbers on the bills that have been introduced. Please bear in mind that the Democrats controlled both chambers in the 117th Congress, and that their agenda was given preference in committees. The opposite is likely to occur in the House in the 118th Congress.

The following bills are those that VOR either opposed, or objected to certain provisions included therein.

H.R. 1319 - The American Rescue Plan Act (ARPA)

ARPA was introduced by John Yarmuth (D-KY) on February 24, 2021 and became law on March 11th. The Act was intended to compensate for losses under the first year of the Covid pandemic. As originally written, the bill granted compensation to Home and Community Based Services (HCBS) for people with I/DD, but no other CMS-approved services, like intermediate care facilities (ICFs) or Skilled Nursing Facilities (SNFs). VOR repeatedly objected to this anti-institutional bias, on the grounds that everyone suffered equally under Covid. We were turned down. Interestingly, education funds were originally intended for public schools, but after heavy lobbying, Majority Leader Chuck Schumer announced that funds would also go to religious schools, private schools, and charter schools, because, "Everyone suffered equally under Covid."

H.R. 4131 & S. 2210 - Better Care, Better Jobs Act (BCBJ)

Introduced on 6/24/21 by Rep. Debbie Dingell (D-MI) and Sen. Bob Casey (D-PA), this was a large spending bill covering, among other things, job creation through investment in infrastructure. Included in this bill was a 10 percentage-point increase in the federal match to state Medicaid payments (FMAP) for HCBS only, again excluding ICFs and SNFs. The bill was later folded into a larger Reconciliation Bill, the Build Back Better Act.

Build Back Better Act (BBB or BBBA)

Like ARPA and BCBJ before it, BBBA originally sought to give a \$400 billion increase in FMAP to HCBS settings only. VOR, Together for Choice and other allies sought parity in the bill, which would have given ICFs and other CMS-approved services a share proportional to their share of pre-pandemic CMS spending. We were told that the funds were for HCBS only, and that funding for other services would have to be added separately – a near-impossible task, given the amount asked for HCBS. The HCBS portion was later reduced to \$200 billion, then \$140 billion, then removed entirely from the bill before it was passed in a severely stripped-down version, providing mostly for infrastructure and supply chain improvements on August 16, 2022.

H.R. 603 & S. 53 – Raise the Wage Act (RTW)

Introduced by Rep. Bobby Scott (D VA) & Sen. Bernie Sanders (I-VT). VOR was neutral on provisions in the Raise the Wage Act that covered increasing the minimum wage, but objected to the inclusion of provisions that would have eliminated or phased out sheltered workshops and compensatory wages as defined under Section 14(c) of the Fair Labor Standards Act or 1938. Other bills to increase the minimum wage were introduced at the same time that did not include the provisions to eliminate 14(c), but were suppressed by committee leadership in favor of RTW. The bill received no Republican support. (Cosponsors: House 202, Senate 37)

H.R. 2373 & S. 3238 - Transformation to Competitive Employment Act (TCE)

Introduced by Rep. Bobby Scott (D VA) & Sen. Bob Casey (D-PA), TCE was a stand-alone bill allocating funds to build competitive, integrated employment programs for people with I/DD while eliminating/phasing out sheltered workshops and 14(c) programs. VOR supports *all* forms of employment for people with I/DD, and worked very hard with like-minded organizations, most notably the Coalition for the Preservation of Employment Choice, to support choice and educate lawmakers that these different forms of employment serve different members of the I/DD and community and that eliminating 14(c) discriminated against individuals with more significant intellectual disabilities who were unlikely to be accommodated by companies offering competitive employment. (Cosponsors: House 63 (5 GOP), Senate 1 GOP)

Review of the 117th Congress *(continued)*

H.R. 1880 - A Bill to Make Permanent the Money Follows the Person Rebalancing Demonstration (MFP)

Introduced by Rep. Debbie Dingell on 3/12/21, this bill received no cosponsors in its original form, yet permanent reauthorization of MFP has appeared in several larger bills throughout the 117th Congress, and is still being promoted by many advocacy groups, including the Arc, ANCOR, ADAPT, and SABE. VOR opposes permanent reauthorization and feels the program has been used to eliminate ICFs, to override individual and family choice and give that choice to legislators. There are several other problems and deficiencies that have been reported and the program needs to be re-evaluated to ensure that the ICF system is maintained, that all of the individuals' needs are met during transitions, that there is sufficient time to return to an ICF placement, and that individuals and families have choice.

S.3417 & H.R.6860 - The Latonya Reeves Freedom Act of 2022

Introduced by Sen. Michael Bennett (D-CO) and Rep. Yvette Clarke (D-NY) the Latonya Reeves Freedom Act was the heir-apparent of the Disability Integration Act from the last 3 congresses. It was written by many of the same proponents of the DIA, which has always called for the elimination of ICFs. In each successive congress, the language calling for phase out/elimination of "institutions" has become more subtle, or perhaps better camouflaged, but remains nonetheless. With the exception of three Republicans in the House, the bill received support only among Democrats (Cosponsors: House 198, Senate 17)

The following are some of bills that VOR supported in the 117th Congress:

H.R. 4761 & 4762 – Restoration of Employment Choice for Adults with Disabilities Act & Workplace Choice and Flexibility for Individuals with Disabilities Act

Rep. Glenn Grothman introduced these two bills to support sheltered workshops, 14(c), and employment choice on 7/28/2021. The only cosponsor was Rep. Jason Smith (R-MO)

H.R. 4779 & S. 1437 – Recognizing the Role of Direct Support Professionals Act

These bills were introduced in 2021 by Rep. Kathleen Rice (D-NY) and Sen. Maggie Hassan (D-NH). The bills would require the Office of Management and Budget to revise the Standard Occupational Classification system to establish a separate code for direct support professionals, a good first step in increasing recognition, training, and improved wages for DSPs. VOR strongly supported these bills. (Cosponsors: House 15, Senate 4)

H.R. 3089 & S. 1544 – Accelerating Kids' Access to Care Act

This was the successor to the ACE KIDS Act from the 116th Congress. It would help minors to access out of state care for treatment unavailable in-state. Although they were not I/DD related bills, they did cover complex medical conditions. VOR signed on in support of these bills. (Cosponsors: House 98, Senate 23)

H.R. 3733 – Essential Caregivers Act of 2021

Introduced by Rep. Claudia Tenney (R-NY) on 6/4/21, this bill would require ICFs, SNFs and inpatient rehabilitation facilities to permit essential caregivers access during any public health emergency. This bill had 81 bipartisan cosponsors.

H.R. 3763 & 3824, S. 2065 - Supplemental Security Income Restoration Act of 2021 & SSI Savings Penalty Elimination Act and S. 4102 SSI Savings Penalty Elimination Act

Introduced in various forms, by Rep. Raul Grijalva (D-AZ) and Sen. Sherrod Brown (D-OH), these bills were designed to amend title XVI of the Social Security Act to update eligibility for the supplemental security income program and increasing the amount of money that people with I/DD receiving Medicaid support could have in their SSI accounts without penalty. Of the two House bills there was only one Republican cosponsor in the second bill. (Cosponsors: H.R. 3763 – 23 / H.R. 3284 – 75) In the Senate, S. 2065 had 22 supporters, none of whom were Republicans. While S. 4102 received only seven cosponsors, they were evenly divided between both parties.

H.R. 6783 - Autism Family Caregivers Act

Introduced by Rep. Grace Meng (D-NY) on 2/18/2022, this bill would authorize the Secretary of HHS to award grants for providing evidence-based caregiver skills training to family caregivers of children with autism spectrum disorder or other developmental disabilities. The bill had 36 cosponsors, all but three of whom were Democrats.

S. 2344 – Supporting Our Direct Care Workforce and Family Caregivers Act

Senator Tim Kaine (D-VA) introduced this bill on 7/14/21, to award grants for the recruitment, retention, and advancement of direct care workers and family caregivers. The bill also included grants for persons in managerial or supervisory positions. The bill had 8 cosponsors, all Democrats.



Still Serving, Still Grateful

By Rita Winkeler

As we approach the end of the year and during this holiday season, I am reflecting on those things that I am most grateful for this year. Immediately what comes to my mind is the large congregate care center our son Mark has called home for over twenty years. Murray Developmental Center, a state “institution”, in southern Illinois has provided Mark with the quality care he needs and deserves. Mark is profoundly disabled, needing 24-7 care with all his personal needs... bathing, feeding, dressing, toileting, etc. At age 38 he is a baby in a big man’s body.....6’3” but functioning as a nine-month-old. He is non-verbal, but can make his needs known by smiling or frowning, and fortunately he is usually smiling. Mark is able to walk, and that is his biggest joy in life. Living on Elm Cottage at Murray Center he has free reign of the cottage, and can usually be found “sunning” near the big front door of the building, or walking around trying to find the best TV program that is on one of the many television sets in the building. Mark has staff taking care of him that have been at the center for over twenty years, and some have been with him since his first days at Murray Center. This is so comforting to parents, as staff become family, and know our loved ones’ needs, sometimes before we do.

Ten years ago, the state of Illinois made the decision to close Murray Center, and to eventually close all the state centers except for one. Their plan after closing the state centers was to close all intermediate care facilities (ICFs), and move everyone with disabilities to small 4-bedroom homes. This attempted closure was met with a huge backlash as families did not want their loved ones moved from their home, and knew that small group homes could not meet the needs of their special loved ones.

The Murray Parents Association, the parent/family group for the center, along with staff, and Friends for Murray Center, a community group, led a huge opposition advocating to keep the center open. This opposition was aided by the help of several legislators.....then Congressman Shimkus, along with other state representatives and senators. Representative Charlie Meier, newly elected, became our biggest champion, as he stood on the Illinois House floor numerous times telling members what was really going on with the closure.....individuals moved to homes with no furniture, homes with holes in the floor, individuals not being fed.....these were just a some of the abuse and neglect that was occurring to those few individuals moved from Murray Center into the 4-bedroom homes.

The MPA joined a lawsuit filed by the Illinois League of Advocates (ILADD), to stop the closure. ILADD is made up of members from all seven of the state centers. Led by our attorney Judith Sherwin, everyone involved held bake sales, rummage sales,

VOR Year End Review – Crisis in Care

The DSP Crisis - The shortage of Direct Support Professionals is the single greatest threat to the sustained operation of our system of care. Whether working in ICFs, group homes, nursing homes, or providing in-home care in family homes or intentional communities or independent living settings, whether serving people with mild or severe I/DD, autism with self-injurious or aggressive/destructive behaviors, or the aging population, there are not enough caregivers to meet the needs of America’s vulnerable populations. The problem has been visible for decades, but has not been addressed on a federal level. We have built a system around an underpaid, overtasked workforce. Simply put, this has been a recipe for failure.

VOR has been working on this issue for years. Recently, we have taken this advocacy a few steps further. We have joined in a coalition of other organizations to present a unified front to Members of Congress. The coalition has agreed to support an increase in wages and training for *all* DSPs in *all* settings – not only HCBS settings, but ICFs, nursing homes, farmsteads, day programs, workshops – everywhere a member of the direct care workforce is helping someone who needs their support, their care, and their love. We support a federal law recognizing DSPs as a distinct classification among healthcare professionals.

The members of this coalition include some organizations we have worked with in the past, allies like Together for Choice and AFSCME, groups representing the aging population, including Leading Age and Caring Across Generations, national groups representing caregivers such as the National Assn. of DSPs, the Domestic Workers Alliance, and the Nat’l. Assn. of State Directors of DD Services, as well as members of groups that have previously opposed VOR, congregate facilities and a full continuum of care, like the Arc and ANCOR.

Coalition-building is not easy, but all of the groups involved have determined that this crisis outweighs our differences, and the best hope of saving our system from completely falling apart is to drop our differences and work together. Only time will tell if this effort can bring federal lawmakers to act, but so far we have had successful, cooperative meetings with the offices of Senators Bob Casey, Tim Scott, Joe Manchin, and Mitch McConnell.

Instead of working against one another, we have chosen to work together, for our DSPs. United, we stand. Divided, we fall.

auctions and more to finance this lawsuit. Very few families moved their loved ones from Murray Center during the attempted closure, and although the families were told that buses would come in and move our loved ones, families held firm. One 82-year-old mother, whose daughter had lived at Murray Center since it had opened fifty years ago said, "If they bring in a bus, I will lay down in front of it before they move Jane". Thankfully she didn't have to do this as Judge Aspen, the federal judge ruled that although the state could close Murray Center, they would have to offer the same services to the Murray individuals. He said, "What are you going to do, build a Murray Center right outside the Murray Center grounds?" The judge ruled in July 2014, and in November 2014 a new governor Bruce Rauner was elected and he stopped all closure attempts.

At that time 203 residents lived at Murray Center. At this time 261 individuals live at Murray Center, and residents continue to be admitted.

Many times, over the past ten years I have been accused, especially by the Illinois Protection and Advocacy group, and other so-called advocacy groups that I want every disabled person to live in a "institution". This is not true at all, as I am also a guardian for my brother, Mark Gerard who lives in a small group home, called CILAs (Community Integrated Living Arrangement) in a town near me. My brother Mark Gerard is highly involved in his community; attending church several times a week, walking to the nearest stores, belonging to the Knights of Columbus, and working at a nearby workshop. He is happy, and his needs are able to be met by the agency, Community Link, that sponsors the homes. Our son Mark, and my brother Mark Gerard prove the saying, "One size does not fit all". Our son needs the round the clock care provided in an ICF, where nurses, doctors, therapists are readily available, whereas my brother Mark Gerard, does not need this type of round the clock care. He is able to care for many of his own needs, with just the supervision of a DSP.



Also, as a Nationally Certified Guardian I am responsible for "being" the person I am a guardian for, which means I have to put myself in their place, and do what I would think they would want done. I am responsible for our son's decisions, as he can't make them, but seeing the smile on his face, and how happy he is every time we visit, I know that if he could tell me he would say that Murray Center is his home, and he wants to continue living there. Visiting with my brother Mark Gerard weekly, I know that he is happy and well cared for in his small group home, and he often tells me he doesn't ever want to move.

So I will continue to be involved in VOR, as the organization is one of the few national organizations that advocate for the full continuum of services.... from the family home to a large congregate care center. Individuals with disabilities have the right to live in a home of their choosing, and these needs should not be ignored or denied. As Judge Aspen said in his ruling, **"In order for there to be choice, that choice has to be available"**. We are grateful every day that in Illinois that choice is available, and both Marks are happy and living their life to the fullest.

- Rita Winkeler serves as both Secretary of VOR and as President of the Murray Parents Group

VOR Year End Review - Continued

Family Caregivers – As a result of the shortage of DSPs, many parents and siblings have had to leave the work force in order to care for their family members with I/DD, autism, or challenges related to aging. VOR has always supported the choice to be a family caregiver, but we are always concerned when choices are made due to necessity, not preference. We support good programs to help family caregivers through training and financial aid, especially those modeled after certain Veterans' Admin programs, but we are concerned that the government is focusing on these programs as a solution to the DSP shortage, rather than addressing both the need for support for family caregivers and the need to support DSPs as two separate crises.

Ohio – We are thrilled to announce that families have managed to protect Ohio's ICFs from the efforts of the state's Protection and Advocacy agency, Disability Rights Ohio (DRO), to undermine the system through the class action suit Ball v. Kasich. Kudos to VOR's Caroline Lahrman and her family for their tireless work and considerable sacrifice. Ohioans have the opportunity to bring DRO before their state legislators every two years, and this year's hearings brought considerable testimony against the agency's failure to protect its most vulnerable individuals by engaging in undermining the choices of their families.

Money Follows the Person – Many of the advocacy groups that oppose congregate care have been rallying for the permanent reauthorization of MFP. VOR urges congress not to reauthorize the program, even temporarily, without it being seriously reevaluated. MFP has been used to erode the ICF system. These funds should be available for those who choose to move into waiver settings. Only. All too often, state officials have used MFP to impose their choices against the will of families who prefer congregate care. As of this writing, Congress has not granted permanent reauthorization to MFP.

Health & Hospital v. Talevski – The Supreme Court is considering whether residents of nursing homes that receive Medicare and Medicaid funds can sue the facilities for abuse and neglect under 42 U.S.C. § 1983, the Spending Clause of the Federal Nursing Home Reform Act. This decision could set precedents for other types of facilities and take away protections for people in ICFs and HCBS settings.

As 2022 is quickly coming to a close, planning for 2023 moves to the forefront. With all but a couple of races decided for the House of Representatives, the Republicans will be in the majority for the 118th session of Congress starting in January. It is expected that 221 of the 435 seats will be held by Republicans giving them a slim vote margin of only around 3. For the Senate, Democrats will retain control of this chamber. If Republicans win the Georgia senate race the Senate will remain tied at 50-50 with Vice-President Kamala Harris breaking any tie votes. If Democrats win the Georgia race, they will have a one vote margin in their majority. This reduces the power of centrist democrats such as Senators Manchin and Sinema and more significantly affects committee structures (see below).

A divided Congress indicates fewer pieces of legislation will pass and heightens the need for bipartisan efforts for any legislative successes. It is difficult to see many legislative vehicles receiving support from both Republican House leadership and Democratic Senate leaders. However, bills may be used to push Members of Congress to take difficult votes based on their district or state. Also, expect to see leadership allow floor votes on legislation in their chamber that they know will not receive a floor vote in the other chamber. Just because legislation is moving in one chamber does NOT indicate it has any chance of becoming law.

Due to the narrow House majority for the Republicans, this side of Capitol Hill will spend time holding oversight hearings for a variety of topics including some addressing healthcare. Program integrity will span numerous committees and areas of interest and will also include healthcare. There is an opportunity here to highlight VOR's priorities and what does and does not work within the I/DD sector.

While Republican leadership in the House will be able to control the narrative for congressional hearings, Senate Democrats will have a similar scenario. The win by Senator Warnock gave Senate Democrats a majority position for committees. In a 50/50 split with no majority, the Senate has to balance the number of members on each committee. With a one-member majority, the party in power can assign more members to each committee, while the minority party has fewer. This means legislation can receive Senate approval without bipartisan support, a critical difference from balance in the 117th Congress. The recent declaration by Senator Kyrsten Sinema to register as an independent appears not to have affected this balance, as Majority Leader Chuck Schumer announced that Sen. Sinema will continue to caucus with the Democrats.

The political reality above will be combined with a background of rising federal debt and interest rates so fiscal restraint is expected to garner attention from Members of Congress. Fiscal constraints will prove to be one more hurdle in passing legislation through Congress, and the debt ceiling will increasingly take legislative time from congressional leadership. The Medicare and Social Security trust funds continue to loom large and will compete with federal spending for congressional support.

Many of the decisions impacting congressional activity will be made by new leadership – particularly in the House of Representatives. Below is a snapshot of key leadership roles for the 118th Congress.

Senate:

Majority Leader: Chuck Schumer (D-NY)

Minority Leader: Mitch McConnell (R-KY)

Finance Committee Chair: Ron Wyden (D-OR)

Ranking Member: Mike Crapo (R-ID)

HELP Committee Chair: Bernie Sanders (I-VT)

Ranking Member: Bill Cassidy (R-LA)

House of Representatives:

Speaker: *expected* -- Kevin McCarthy (R-CA)

Minority Leader: Hakeem Jeffries (D-NY)

Energy & Commerce Chair: Cathy McMorris Rodgers (R-WA)

Ranking Member: Frank Pallone (D-NJ)

Labor & Education* Chair: Virginia Foxx (R-NC), Tim Walberg (R-MI) or Jim Banks (R-IN)

Ranking Member: Bobby Scott (D-VA)

Ways & Means Chair: Vern Buchanan (R-FL), Adrian Smith (R-NE), or Jason Smith (R-MO)

Ranking Member: Richard Neal (D-MA)

**Typically called House Education & Workforce when Republicans are in the majority*

As VOR looks to update priorities for the 118th Congress to bring awareness and federal support for various programs, working within the realities of the landscape will maximize your efforts.

Capitol Hill meetings should prioritize including VOR members who are constituents. A “fly-in” is fantastic, but continued engagement is key to establishing and continuing positive working relationships with both staff and members. While in-person meetings with congressional staff are usually the most effective way of making a memorable impression, Zoom meetings have become common on Capitol Hill, and have proven to be an effective way to communicate.

Those who find it difficult to meet with their elected officials in D.C. whether in person or on Zoom, may prefer to schedule congressional visits “back home” to expand knowledge and deepen understanding of VOR’s request and your members’ needs. While in-state staffers be less familiar with federal legislation, they are usually better informed on in-state issues and better suited to arranging a visit to your loved one’s facility. An on-site visit, can also be coordinated to align with the D.C. hill staffer’s visit to the district or state,

Work with staff to spotlight your concerns using committee hearings. Personal experiences combined with data (or highlighting the need for more data) are impactful. VOR can also submit questions for the record via members to help push agencies to answer critical questions.

Look for areas of agreement and collaborate with others to maximize your efforts and progress. 14(c) and the tight labor market are two excellent examples.

The COVID-19 public health emergency (PHE) will continue into 2023. The Biden Administration has promised 60 days’ notice before ending it (each renewal last 90 days). Many waivers that have been allowed due to the PHE have become commonplace over the past few years. However, it would take congressional action to extend or make them permanent (ex. Telehealth).

Legislation addressing PHE related waivers has an edge over other healthcare bills, and it may allow other bipartisan healthcare policies to be included. Even here costs will be key.

As with each Congress, international events and the unexpected will play a role. Further, setting aside the political and fiscal realities, the 118th Congress could choose bipartisanship over partisan talking points. Being alert to shifts in focus and various federal opportunities can garner wins to improve the lives of the I/DD community.

Gayle Gerdes works at the Washington, D.C. lobbying firm Health Policy Source, and serves as a legislative advisor to VOR

VOR Year End Review –The State of State ICFs

VOR has fought for years to protect the ICF system nationwide, understanding that they may be the most appropriate care setting for some individuals with severe/profound I/DD and autism. State-operated ICFs are truly the safety net in the system, though many states have decided to abandon their programs and turn the care of our loved ones entirely over to a privatized system. Recently, the following states have drawn the attention, and concerns, of VOR families:

Pennsylvania - Two years ago, Gov. Wolf and DHS Commissioner Teresa Miller announced the closing of the Polk and White Haven Developmental Centers. VOR supported the keeping the facilities open, by testifying before the State Assembly and Senate and donating to the families’ lawsuit. Legislators overturned the Governor’s decree, but fell short of votes to overturn his veto. Families were ultimately granted class standing in the lawsuit, but were not granted injunctive relief, effectively allowing the state to transfer individuals to other facilities. The court case is still being appealed, but the centers are nonetheless slated for closure and the state has been moving residents out at an alarming pace.

Iowa - The Glenwood Resource Center has been the subject of investigations by the Department of Justice for several years, following disturbing reports of experimentation conducted by a previous administrator. DOJ renewed its investigations following incidents of abuse and neglect at the facility and has initiated further actions against the state’s Dept. of Human Services, including charging the state with a failure to sufficiently support HCBS programs. Earlier this year, after having insisted repeatedly that Glenwood would remain open, Governor Kim Reynolds and Iowa DHS abruptly announced the facility would close in 2024.

Families are being forced to make some very hard choices. VOR has tried, unsuccessfully, to encourage the state to encourage the creation of new private ICFs, but the state’s hands are tied by the terms of DOJ’s proposed settlement. We continue to attend virtual town halls to support families of alternatives, and to keep them informed of their rights to ICF care.

North Carolina – Last month, a Superior Court judge issued an injunctive relief order in the case of Samantha R v. North Carolina. Samantha’s group home had been closed, and she was moved to an ICF for services. The state’s P&A, Disability Rights NC, sued based on lack of HCBS facilities, in effect blaming the safety net of ICF services for working properly while the HCBS system they supported continues to fail. The judge ordered the state to resolve the 16,000-person waiting list in 10 years and allow new admissions to ICFs only on a temporary basis (6-month maximum). VOR is trying to find a way to engage, provided we can find a legal basis to intervene and families willing to engage.

**VOR is a national, non-profit 501(c)(3) volunteer organization
speaking out for people with intellectual and developmental disabilities**

The VOR Voice – Winter, 2022

In this issue:

- A joint message from our President and Executive Director
- A Review of the 117th Congress
- Rita Winkler on gratitude for a full continuum of care
- Updates on VOR's current issues and advocacy
- Gayle Gerdes' looks at the 118th Congress

Please note: Your membership expiration date is listed at the bottom of the address label above

Membership / Contribution Form

Mail this form to: VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007

Fax to: 877-866-8377 or donate online @ <http://www.vor.net/get-involved>

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☐ \$200 per year per family organization

☐ \$250 per year per provider / professional org.

☐ I would like to make monthly donations to VOR. Please charge my credit card each month for: \$ _____

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