

President's Message

Year 2019 is quickly coming to a close and I hope it has been as exciting a year for each of you as it has been for me. I realize that most of you are not familiar with the picture you see to the right of the page as you begin reading this message so real briefly I will introduce myself to you.

I am Darrell Pickney from Hoxie, Arkansas. I have been advocating on behalf of the I/DD population most of my adult life, primarily due to my oldest daughter Darlene being born in 1965 with a severe intellectual disability. She spent most of her teen and adult years living in wonderful state operated ICF's and unexpectedly passed this life due to a heart attack in February of last year.



In Arkansas as a member of Family & Friends of Care Facility Residents (FF/CFR) for over 25 years we annually battled state legislative initiatives in an effort to protect and maintain rights for our loved ones. This is where I first learned of VOR and realized they were battling the same type of issues on a national level that we were battling in Arkansas. To support this national organization, I joined VOR in 2010 but remained an inactive member for the most part, up until now. Since joining in 2010 I have attended some of the annual conferences in Washington D.C., enjoyed visiting with the Arkansas Congressional delegations on Capitol Hill, became acquainted with the VOR leaders of the particular year, and became more and more interested in the wonderful work being accomplished by VOR.

In early spring of this year I was invited to fill a vacancy on the VOR Board of Directors and during this June's Washington Initiative the membership elected me to the office of President. It's hard to believe that was nearly six months ago. It seems almost like yesterday. I officially took office on July 1st along with several other new Board members. Working with a mixture of veteran members and new members has been a real blessing. I have learned so much from the experience and knowledge of the senior members while being truly inspired by the energy and exciting ideas of the newer ones. I truly believe this blend of unique talent bodes well for the future of VOR.

I shared my story with you for a very particular and important reason. As we close out the year, we are nearing the end of our 2019 Membership and Fundraising Drives. If you are reading this and ARE NOT a member of VOR I am giving you a personal invitation to join today. The larger our membership is, the stronger our voice will be, when we do our work on behalf of the I/DD population at the State Capitols across the country and on Capitol Hill. Whether your desire is to join and become actively involved, or you are satisfied to join and remain inactive as I did for several years, either way your membership is so important to our cause. You can go to www.vor.net for more information on joining our organization.

If you are reading this as a current member, I thank you from the bottom of my heart. I also encourage you to become as involved as you are willing to be. We want you to communicate with your officers and board members in person when you can or via e-mails, texts or telephone. Let us know about your and your state's issues. We also need your thoughts and ideas on how we can better serve you.

HAPPY HOLIDAYS and may GOD BLESS YOU AND YOUR FAMILIES.

A handwritten signature in dark ink that reads "Darrell Pickney". The signature is written in a cursive, flowing style.

Darrell Pickney
President, VOR Board of Directors

Abuse and Neglect of Vulnerable Populations Widely Recognized: Mandatory National Background Checks for Direct Support Professionals Needed

Submitted by VOR's Issues/Oversight Committee

In support of its voluntary national background checks program for states, the Centers for Medicare & Medicaid Services (CMS), noted that “long term care (LTC) patient abuse, neglect and misappropriation of funds have been identified as a widespread problem for millions of Americans receiving LTC services.”

<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/BackgroundCheck.html>

Reports from federal agencies and news media have raised continuing serious concerns about the quality of LTC services:

In 2003, the Government Accountability Office report “Long Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened”, found that *more than 70 percent of the programs it reviewed had problems with quality of care*. <https://www.gao.gov/new.items/d03576.pdf>

In 2012, a report entitled “General Oversight of Quality of Care in Medicaid Home and Community-Based Services Waiver Programs”, from the Department of Human Services, Office of Inspector General states that adequate systems to ensure quality of care are lacking in many states. <https://oig.hhs.gov/oei/reports/oei-02-08-00170.pdf>

In 2018, a joint report, “Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight”, issued by the U.S. Department of Health and Human Services, Office of Inspector General (OIG); Administration for Community Living (ACL); and Office for Civil Rights (OCR) states “OIG found that health and safety policies and procedures were not being followed. These are not isolated incidents but a systemic problem – 49 States had media reports of health and safety problems in group homes.”

<https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf>

The opportunity for caregiver abuse has grown along with the numbers of individuals with intellectual and developmental disabilities (I/DD) receiving Medicaid home and community-based (HCBS) supports. According to the 2018 report “In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and Trends” nearly half of the 807,462 current Medicaid HCBS Waiver recipients with IDD receive supports from non-family caregivers. The report also states that between 1977 and 2016, the number of non-family IDD settings increased from 11,008 to 229,076 settings. <https://risp.umn.edu/>

Another report shows that abuse is widespread, including at the hands of caregivers. A 2016 report reviewing the Medicaid Personal Care Services program exposes fraud and abuse of elderly persons and persons with disabilities. <https://khn.org/news/seniors-suffer-amid-widespread-fraud-by-medicaid-caretakers/>

VOR is grateful to Congress for its past support of national background checks. The 2003 Medicare Modernization Act (Section 307) provided for a demonstration program, and the 2010 Affordable Care Act's national background check grant program was even more robust.

The CMS voluntary national background check program for states is only as good as the number of states that receive grant money. Currently, only 26 states receive these funds.

<https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/NBCP-State-Award-Chart.pdf>

An April 2019 report by the Office of Inspector General, U.S. Department of Health and Human Services, entitled “National Background Check Program for Long-Term-Care Providers: Assessment of State Programs Concluded 2017 and 2018” reviews the progress of these grants. <https://oig.hhs.gov/oei/reports/oei-07-18-00290.pdf>

Until every state participates, however, there are opportunities for “bad apples” to be employed or re-employed by other providers and continue working with vulnerable populations in non-participating states.

Building on the existing voluntary program and existing state law, a mandatory national background check program for all direct care workers of all Medicaid long-term care homes would help ensure consistent staffing expectations across all care settings and states, making residents living in LTC homes safer. Ohio offers one good model for a state background program, though there are several other states that measure up, as well.

https://www.vor.net/images/stories/2019-2020/Ohio_Background_Checks.pdf

I was speaking with a friend the other day. He spoke of his frustrations and disappointments over the years - how the funds appropriated for services never keeps up with the real cost of services, how money that should go to direct care gets diverted to other pockets in what has become the "disability industry", how waiting lists have continued to grow each year, and, of course, how so many ICFs have been closed over the past thirty years. "What's the use?", he asked. "The other side has far more money. They've bought the politicians. They run the DD Councils and the P&A's, they run HHS and CMS and ACL and DOJ and all of the university studies. Why do we knock ourselves out trying to fight them all?"

Well, we all know why we do this. We do it for our sons and daughters, brothers and sisters with Intellectual and Developmental Disabilities. We do it for others we aren't related to, but who we know need our help. We do it for everyone who needs services and doesn't receive the care they need. We do it for the families, to ease their burden just a little, to let them know that they are not alone. We do it day after day, week after week, year after year.

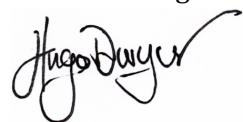
So how do we keep a positive attitude?

First of all, we need to always remember that we are right. No matter what anyone tells us, no matter how often they try to tell us we are wrong, that they know better, that the cost of high-quality care is too high, or that equivalent services are provided in other settings, we have to remember our own experience. We have to remember that *we are not wrong*, that *we are right*, even if it seems we are the only ones who recognize that fact.

Second, we have to remember that we cannot measure our good works by counting our losses. Yes, we can count the number of ICFs that have been closed over the years. We know of farmsteads or intentional communities have been deemed not integrated enough to meet the criteria of the ***inclusionistas***.

Our victories, our real successes, can rarely be counted. How many ICFs did not close as a result of our advocacy? How many people were not subjected to abuse because of our ongoing efforts to improve national background checks? How many families learned that they were not alone, that they could join together and speak as one voice? How many people in Illinois still benefit from ICF care after the Ligas case was settled in our favor, or in Arkansas as a result of the hard work of the families who fought the closure of the Conway Human Development Center? Even when we lose a case, such as the closure of two ICFs in Virginia, how many people may have been protected because the families involved got better terms in the settlement as a result of their hard-fought negotiations with DOJ? Even though fourteen states no longer offer ICF care, we've held off the forces of closure in states all across the country. And lest we forget, **how many people benefited from the *amicus* brief that VOR submitted that was included in the Supreme Court's landmark decision in *Olmstead*?**

How many people with I/DD or autism, Down Syndrome, Fragile X, or Cerebral Palsy have benefited from our work? We will never know. We don't need to know. Because we do know that we have helped many, and that we have done what we know is right. And we can use that knowledge to keep a positive attitude and move forward, to fight another day.



Hugo Dwyer
Executive Director, VOR – A Voice Of Reason



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VOR Joins with Together For Choice in Washington, D.C.

On November 13th and 14th, VOR's First Vice President Joanne St. Amand and Executive Director Hugo Dwyer joined with members of Together for Choice and their legal counsel to advocate in congressional offices for people with intellectual and developmental disabilities (I/DD). Our focus was on promoting a full continuum of care in residential settings, with emphasis on the new guidance CMS made to the Settings Rule, and for protection of employment opportunities for people with I/DD include both competitive employment and work centers that operate using compensatory wages under Section 14 (c) of the Fair Labor Standards Act (FLSA). In several offices, we also discussed our objections to the elements of the Disability Integration Act that would close ICFs and other congregate settings.

Last March, CMS relaxed the guidelines for the Settings Rule, allowing for farmsteads and intentional communities, as well as relaxing rules governing the allowable proximity from one waiver setting to another, or from one waiver setting to a non-waiver setting for individuals with I/DD. Unfortunately, most states are still following the 2014 guidelines promoting a more rigid adherence to inclusion and forbidding congregate settings, like intentional communities and farmsteads, and prohibiting waiver settings from being too close to other one another or to any congregate settings. While the new CMS guidelines are an improvement over the previous restrictions, VOR and TFC agree that the settings are still too restrictive and lacking in clarity, resulting in different interpretations of the rules by different states. Our joint "ask" on this issue was that states sign on to a letter encouraging CMS to further clarify the new guidelines to state disability services agencies, and ensure that they are no longer adhering to the older, more restrictive rules.



L - R: TFC's Rosemary Huether and Mike Guerrisi, James Damon of Covington Burling - legal counsel for Together for Choice, TFC's Jody Weaver, VOR's Hugo Dwyer

settings rule, CMS and the state of Pennsylvania will only pay for her son's care if he is in a group home, despite clear evidence that he thrives in the congregate, constructive environment of the farmstead.

It was an eye-opening experience for Joanne and me to see how Intermediate Care Facilities aren't the only residential options that are considered "too isolating" or "not integrated enough" for people with I/DD.

In addition to the Settings Rule, we spoke on behalf of people who benefit from the opportunity to engage in meaningful work through compensatory wages as governed by the Department of Labor under Section 14(c) of the FLSA. In addition to Covington Burling's one-sheet on the issue, we passed out Harris Capps' article on the importance of these settings to people like his son Matt (*see article on opposite page*). We also met with aides in Senator Chuck Schumer's office and Representative Frank Pallone, Jr.'s Health Counsel for the House Committee on Energy and Commerce to discuss VOR's objections to the Disability Integration Act.

Our last meeting was with an aide to Joanne's congressman, Representative Van Drew of New Jersey. It turned out that, prior to his political career, Rep. Van Drew had worked for many years as a dentist. We took a moment to speak with him about our concerns regarding the lack of quality dental care available to people in "the community", and we plan on following up to see if there might be some way to work together to help create a program to incentivize more dentists to serve people with I/DD.

The Families in this picture have had their boys at Camphill, a farmstead in Pennsylvania. Recently the boys have all aged out of the facility and been forced to move to alternative housing. Their stories are devastating. Mike Guerrisi and Jody Weaver's twin boys have been forced into a group home, which has not provided any constructive programs like they had engaged in at their farm-stead at Camphill. As a result of the lack of activities available in the group home, the twins' aggressive behaviors have re-emerged, and they have gained weight. The group home environment has been isolating and has caused the two young men to regress.

Rosemary Huertha's family has been forced to pay out of pocket to keep her son in a farm-based environment, because CMS won't cover this option. Her son continues to thrive in this setting, though the financial burden on the family is tremendous and hard to sustain. Despite the new guidelines in the



L - R: VOR's Hugo Dwyer and Joanne St. Amand, Rep. Jeff Van Drew of New Jersey, and Chris Lowther of Covington Burling, legal counsel for Together for Choice.



SAVE THE DATE!

VOR's 2020 ANNUAL MEETING AND LEGISLATIVE INITIATIVE

JUNE 7 – 10, 2020

HYATT REGENCY CAPITOL HILL, WASHINGTON, D.C.

An Existential Threat Against the Significantly Disabled

Phase-Out of Vocational Centers (*Sheltered Workshops*)

By Harris Capps, VOR, November 2019

I am a Parent and Guardian for my son, Matthew, who has moderate to severe Intellectual and Developmental Disabilities (IDD), to include autism and cerebral palsy that precludes speaking. He also has behavioral episodes that may range from tantrums to severe meltdowns that could result in injury to himself or others. Just explaining that to you is painful, because his dignity is important to us. He resides in an Intermediate Care Facility (ICF) which provides 24-hour care. He is largely unable to understand how to reason or make decisions. He knows that a dollar will help him go to MacDonald's, but he has no concept of how many dollars and cents may be required.

The very existence of Sheltered Workshops for those with Intellectual and Developmental Disabilities (IDD) has been attacked for the first time since the law was enacted in 1938 as a part of the new Social Security Program. Why do higher functioning disabled persons and their lobbying organizations want to deny lower functioning persons, the right to work? If a higher functioning individual can get a job that provides a mandated minimum wage, surely, they already have the minimum wage law in effect to protect them. So, let me tell you a bit more about Matt.

Matthew loves to go to work at "PERCO", a vocational Center in Perry County, Ohio. If we call him on Sunday evening and remind him that he gets to go to work the next day, he quite literally jumps up and down and makes sounds of anticipatory delight.



According to his job coaches, Matt is very proud that he accomplishes work and earns a paycheck. Matthew is unable to differentiate the amount of his check... he just revels in the fact that he has earned something of value which allows him to pay for things. If a picture is worth a thousand words, do you think this photo of Matt working conveys dissatisfaction or sadness?

The following episode tells you the importance of his work. On a Saturday in February 2019, Fran and I got a call from nursing at Matt's ICF. Matt had made the sign (crossed arms) for "work". In other words, he wanted to go to work. But his Work Center is not open on the weekends. The direct care worker tried to explain to Matt that the Center was closed. Matt quickly went from a somewhat manageable tantrum to what we call a "meltdown" typically

evidenced by his inability to control his emotions, yelling, crying, and in this case, he bit his direct care worker on the arm. The worker had to go to the hospital for treatment.

Supporters of "14 (c) Work Centers know many **Myths** for phasing-out the Sub-minimum Wage including self-determination. For example, it is simply **untrue** that "employers across the country are using this waiver to acquire cheap labor". And, the **false assertion** that my son is somehow a victim of discrimination, and exploitation. Matt voluntarily attends a sheltered workshop because it fits his capabilities. People with IDD like Matt would never be able to work in "competitive employment" because his measured productivity (monitored by the Department of Labor) is too low, and for what he does achieve, he requires job coaches to teach, encourage and know how to deal with his disabilities.

In a 2018 editorial in The Hill, David Ordan of the Disability Service Provider Network wrote:

"In 2014, 75 percent of individuals with I/DD receiving day or employment services through a state I/DD system were attending a sheltered or facility-based environment.

This means that efforts to remove 14 (c) subminimum wage certificates are essentially targeting one group, and one group alone: people with disabilities who choose to attend sheltered workshops".¹

He further explains that follow-up studies have shown the failure of closing Work Centers, like in Maine where, over seven-year period displaced persons not able to obtain employment increased "Day Program" enrollment from 550 in 2008 to 3,178 in 2015.

Mis-informed *logic* ignores important subjective standards such as empathy, compassion and personal values resulting in treatment of folks like Matt as an individual. In 1938, persons who had just suffered through the Great Depression used not only logic but also their values to say that **Matthew Matters**.

¹ "Eliminating Subminimum Wage Waivers Will Harm Hundreds of Thousands of People with Disabilities" By David Ordan, The Hill, August 10, 2018 <https://thehill.com/opinion/healthcare/401273-eliminating-subminimum-wage-waivers-will-harm-hundreds-of-thousands-of>

Preventing Abuse and Neglect of Individuals with Intellectual and Developmental Disabilities

We all understand that abuse and neglect can happen in any type of setting. It can happen in large facilities, small facilities, a person's own home, even a family home. We have the right to expect that it will not happen to our loved ones, but we know that it can happen. Every state has a Protection and Advocacy agency (P&A). Every state has a Department overseeing Human Services or Disability Services (DHS, DDS). It's not supposed to happen, yet it happens all the time.

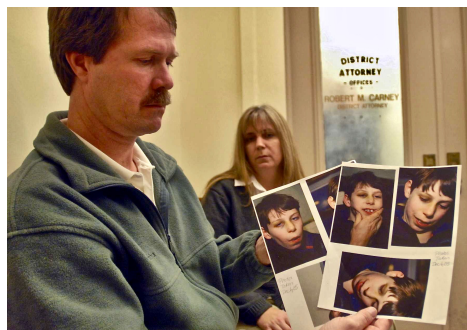
How can we prevent, or lessen the likelihood of incidents of abuse and neglect?

1. Improve the quality of the workforce. This can be achieved by demanding rigorous state background checks for caregivers in all roles, by promoting education training for Direct Support Professionals, and for increasing the pay for DSPs and providing career incentives.
2. Improve the quality of reporting of abuse and neglect. Poor reporting of incidents of abuse and neglect need to more incidents of abuse and neglect. When incidents occur, we must make sure that those responsible are held to account, but we must also make sure that those responsible for investigating the abuse are held to account. Where was P&A when this happened? Did they investigate the provider, and the provider's other homes? What actions have the administrators at DHS taken to ensure that this won't happen again?
3. Make sure that the state has strict laws governing the reporting of incidents, provides timely notifications to parents and guardians of the individuals who suffered the abuse or neglect, and makes sure that all stakeholders are provided with detailed information regarding the proper procedures for reporting incidents and informing them of their rights under law regarding notification of incidents.

What are the laws in your state? What can you do to make sure your state's laws meet your expectations for the safety and care of your loved ones?

Michael and Lisa Carey - Jonathan's Law and the Fight for Oversight and Accountability in NY

On February 15, 2007, Michael and Lisa Carey received word no parent should have to hear: Their son Jonathan was dead.



In 2004, Jonathan had been attending the Anderson School in Staatsburg, New York. Jonathan had severe autism, and was non-verbal. When his parents became aware that Jonathan had been abused at the school, their demands to see his records were denied. They transferred him to the O.D. Heck Development Center outside of Albany. It was there that Jonathan died while being taken to the mall by two Center staff members who used an improper restraint on him while in the van. The workers failed to seek medical attention for 90 minutes after the restraint. The driver of the van pleaded guilty to criminally negligent homicide and was sentenced to six months in county jail. His co-worker, who restrained Jonathan, was convicted of 2nd degree manslaughter and sentenced to 5 - 15 years in prison.

Since Jonathan's death, his father Michael has been a relentless advocate of reforming the state's oversight of the developmentally disabled in its care. In May, 2007, he changed the state law regarding parents', spouses', guardians', and other qualified persons' access to records relating to incidents involving family members residing in facilities operated, licensed or certified by the Office of People With Developmental Disabilities (OPWDD) and other state agencies. Reportable incidents include physical, sexual or psychological abuse, or neglect, as well as incidents that may result in or have the potential to result in harm to the health, safety or welfare of a patient. The changes to the existing law are now officially known as **Jonathan's Law**.

The effort continues. In November, 2019 NYS Comptroller Thomas DiNapoli issued the second of two audits showing that a significant number of incidents of abuse and neglect were still not being reported in accordance with Jonathan's Law.

Michael is currently spearheading an effort requiring those facilities to call 911 in the event of abuse or neglect. Instead of calling 911, facilities are directed to NY State's *Justice Center*, a state agency created in 2012, to investigate and prosecute cases of abuse and neglect in state facilities. He claims the Justice Center intentionally excludes local law enforcement, and does not properly investigate or prosecute cases of abuse and neglect.

"The death of Jonathan was tragic and brought about some changes in the mental health system, yet, here we are ten years later and there have still been no significant changes," he said. "Most crimes against the disabled are still not being prosecuted."

<https://www.justicecenter.ny.gov/system/files/documents/2019/03/jlawenglish042017.pdf>

Jonathan's Law consists of amendments to New York Mental Hygiene Law Article 33 that:

- Give parents and guardians of developmentally disabled people who live in government-licensed facilities access to records concerning abuse allegations. Records must be produced within three weeks after an investigation is closed;
- Mandate telephone notification, within 24 hours of an incident, to parents or guardians, followed by a written report within ten days;
- Require facility directors to meet with parents and/or guardians to discuss reported incidents; and
- Increase fines for noncompliance to \$1,000 per day and up to \$15,000 per violation.

The Battle for Pennsylvania

On April 30th of this year, the Pennsylvania State Legislature held hearings in favor of opening up the state's four remaining Developmental Centers to new admissions. Testimony was given by Susan Jennings and other parents, guardians and caregivers of the residents in the centers, along with members of VOR and other groups. A small contingent of people opposed, most from the state chapter of a large, well-funded national organization, voiced their opposition and their feelings that, even though not stakeholders at the centers, they did not have enough of a say in the discussions as they felt entitled to have. Overall, the tenor of the hearing indicated that several legislators recognized the need for this level of care and for expanding the state's capacity to address the needs of people with this level of intellectual disability, behavior disorders, and physical and medical challenges.

Three and a half months later, on August 14th, Governor Tom Wolf and Secretary of the Department of Human Services Teresa Miller announced that they had determined to close the White Haven and Polk Developmental Centers. Their decision was made behind closed doors. The State Legislature, the residents of the Centers, their families and guardians, their caregivers, the union, the administrative staff of the centers, and the town councils and chambers of commerce of the communities around the centers – the stakeholders of the Polk and White Haven Centers – were all kept out of the decision-making process. It is not known whether anyone from the large, well-funded organization took place in the discussions, but the director of said organization seemed very pleased, smug even, about the decision that her friends had made to throw over 300 vulnerable people out of their long-established homes and to move over 700 hard-working, dedicated staff members out of their jobs. The stakeholders of the Polk and White Haven centers were furious.

Thankfully, members of the State Legislature have taken it upon themselves to look into the matter. They held hearings to determine how the decision had been made, why stakeholders had been deliberately excluded from the process, and what steps to take to postpone or override this disastrous decision. A bill was proposed to put a moratorium on closing any of PA's centers until everyone on the state's waiting list has received the services they have requested. The bill passed the state's Senate with a veto-proof majority and now goes before the state's House. Advocates are reaching out to their assembly members to stand up for the right to quality care in the state's ICFs.

If you live in Pennsylvania or have a loved one at one of the centers, please write to your state representative and ask her (or him) to support the bill, SB 906. If you live outside of the state, you may help by donating to their GoFundMe page at: [gf.me/u/wkqjum](https://gofundme.com/f/please-help-save-our-pennsylvania-state-centers?utm_medium=copy_link&utm_source=customer&utm_campaign=p_lco+share-sheet) (gf.me/u/wkqjum) or https://www.gofundme.com/f/please-help-save-our-pennsylvania-state-centers?utm_medium=copy_link&utm_source=customer&utm_campaign=p_lco+share-sheet

Preparing for the Next One

When Pennsylvania Governor Tom Wolf and Secretary of the Department of Human Services Teresa Miller announced their decision to close the Hamburg Developmental Center on January 11, 2017, there was no single group or organization in the state to stop the closure. The head of the Hamburg Center's family group made a deal with the department to ensure that his loved ones received placements in group homes nearby, and all of the other families were at the mercy of Teresa Miller to find new homes.

VOR staff called members around the state, to see if any individual or group was positioned to stand up against the closure. The last organized group in the state had fought the 2009 class action lawsuit Benjamin v PA, which was settled in 2012. While still vigilant over the terms of their settlement, the families involved had dispersed and were no longer in touch. There was no current organization on the ground to defend the Hamburg families, though several individuals, including 93-year-old Polly Spare, Past President of VOR, did travel to the Center to protest the closure.

Hamburg Center closed on August 3, 2018. Of the 80 people who lived at the center when the closure was announced, six died before the closing occurred and eleven died since transferring out.

Thank heavens for Susan Jennings, who put together an organization, KIIDS (<https://thekiids.org>), and gathered families and advocates to prepare for the next closure. This time, they were ready. Still outnumbered. Still outgunned, but at least organized and ready.

So what about your state? Are there any organizations uniting families? Caregivers? Do the people at one end of the state know what's going on at the other end, or in different facilities? If not, then now might be a good time to start working on that effort. Feel free to reach out to our State Coordinators for suggestions as to how you can get involved. <https://www.vor.net/about-vor/state-coordinators> If you don't see your state on the list, or if you can't get through, please contact Rita Hoover at rhoover0506@sbcglobal.net or Rita Winkeler at ritawreads@gmail.com

Protect Medicaid For Our Loved Ones With Intellectual and Developmental Disabilities

Medicaid Long-Term Services and Supports (LTSS) as we have known them, are in danger of drastic changes in the years to come. Many of these changes have already been initiated; others are looming on the horizon. The Center for Medicare and Medicaid (CMS) estimates 20% of Medicaid spending goes to LTSS. As of July, 2019, Medicaid (together with CHIP) provided coverage to about one in five Americans, or about 72 million people. Total Medicaid spending was \$593 billion in FY 2018 with 62.5% paid by the federal government and 37.5% financed by states. Medicaid accounts for one in six dollars spent in the health care system and more than half of spending on long-term services and supports.¹

That's a lot of money, both for states and for the federal government. Below are three threats to the system that our members should be aware of.

Federal Cuts – The most obvious threat to Medicaid would be to reduce funding to the program overall. Most Americans are aware that this has been a stated goal of the current administration, which has promoted tax cuts and openly declared its intention to cut social safety net programs like Medicare, Social Security, and Medicaid. As the country now faces a \$1 trillion deficit, it is likely that cuts to all of these programs will be proposed in the budgets for the coming years.

Block Grants and Per Capital Spending Caps – Alaska and Tennessee are already working on this, and CMS Administrator Seema Verma is working on setting the guidelines for block grants to states. Under a block grant, states would be given more flexibility to design their own Medicaid program. States could decide who is eligible for the program and what services are covered. Proponents claim that block grants could save the federal government billions. Unfortunately, these savings might mean gaps in services. While the block grant amount grows annually with inflation adjustments, medical inflation is often higher and so the growth in block grants is unlikely to keep up. As a result, most states would see a decrease in funding.

Per Capita spending caps work in a similar manner, limiting the amount the federal government would pay to a mathematic formula based on the number of people qualifying for services multiplied by the average cost of services. The problem here is that for those whose expenses exceed the norm, there may be cuts to the services they receive in order to accommodate any increase in the number of people who qualify for services.

Managed Care for Long-Term Supports and Services – Many states have switched to managed care for the majority of their standard Medicaid services. Several states are also in the process of moving to Managed Care for Long-term care. As opposed to traditional fee-for-services payments, which states pay out according to the amount of care provided, Managed Care is another “lump sum” payment cap, much like block grants and per capita caps. States like these programs, as it makes it easier to pass their annual budgets and to refrain from exceeding those budgets in Medicaid expenses. It also means the state will not be the one denying Medicaid recipients the services they require or request. Denial of services will fall to the managed care providers.

Managed care moves the provision of services from the government to large private insurers, some with shareholders (for-profit) and other without (non-profit). Despite the classification, both of these types of entities are out to make a profit by keeping some of the money apportioned to the care of Medicaid recipients for themselves. They claim to do so through applying more efficient business practices to their routine. For the most part, their system would rely on denying services, cutting services, and a maintaining a low-pay model for Direct Support Professionals, including maintaining a minimum wage workforce of poorly trained caregivers and cutting rates for doctors and nurses. One can easily imagine the consequences this would have for our loved ones with I/DD.

In addition, managed care companies need time to build their systems and take over the day-to-day responsibilities of running a statewide system of services. However, when managed care companies determine that it is no longer profitable for them to provide services within a state, their departure is usually relatively swift. The same applies for when a state determines that a managed care provider is providing poor services and discontinues their contract.

For further information on the problems anticipated by LTSS moving to managed care, please see the article Dr. James Edmondson wrote in the Spring Issue of the VOR Voice² or watch the video of the presentation he made at our annual meeting last June.³

¹ Kaiser Family Foundation - <https://www.kff.org/medicaid/report/a-view-from-the-states-key-medicare-policy-changes-results-from-a-50-state-medicare-budget-survey-for-state-fiscal-years-2019-and-2020/>

² https://www.vor.net/images/stories/VOR_VOICE/Spring-2019.pdf

³ <https://www.youtube.com/watch?v=vr0r0OcFgy0&list=PLdENLQViuorVtN0GfAUnejMBU6fogGZbA&index=2>

Update on Congressional Activity

Here are a few of the bills VOR has been watching, and a brief description of why we support or oppose them:

VOR SUPPORTS:

H.R. 2417 - The HEADs UP Act - To amend the Public Health Service Act to expand and improve health care services by health centers and the National Health Service Corps for individuals with a developmental disability as a Medically Underserved Population (MUP).

H.R. 4280 – The Supplemental Security Income Restorative Act – To amend Title XVI of the Social Security Act to increase the amount of disregarded income that beneficiaries can take in each month, and to repeal penalties for marrying or receiving financial, food and housing assistance from family members.

VOR OPPOSES:

H.R. 555 & S. 117 - The Disability Integration Act - This bill has written into it the goal of eliminating "institutional care". In addition to the inherent bias against ICF's and people with severe and profound I/DD, the bill is prohibitively costly and there are not enough Direct Support Professionals to meet the provisions of this act.

H.R. 582 & S. 150 - The Raise the Wage Act - This bill is aimed at raising the minimum wage, but it also has provisions to eliminate 14 (c) wage certificates over the next six years and to immediately stop the issuing of any new certificates. VOR believes the issue of employment options for individuals with intellectual disabilities should not be buried in a bill for raising the federal minimum wage. Both issues deserve clean, stand-alone bills.

H.R. 873 & S. 260 - The Transformation To Competitive Employment Act - This bill has declared the goal of eliminating Sheltered Workshops and 14(c) Wage Certificates, under the mantle of everyone with a disability is capable of competitive integrated employment.

Money Follows the Person Reauthorization Act (MFP) – Currently, renewal of MFP resides in the Appropriations bill, which has not been formally passed, due to disagreements on funding for the border wall. MFP is expected to be funded through 2021 upon passage of that bill. At this time, there is no Authorization bill to renew MFP for a longer period, but we expect there will be companion bills entered in the House and Senate next year. VOR opposes MFP as it has been used by states to close ICFs and override the ability of individuals, families and guardians to make their own choices for residential care.

A Reminder to Families about Guardianship and Supported Decision-Making

There is a national effort to promote Supported Decision Making (SDM) as an alternative to court appointed guardianship. SDM promotes the idea that, with almost no exceptions, all people with intellectual disabilities can make their own decisions with support from an informal network of advisors. The advisors do not need to be court-appointed and do not bear any responsibility for ensuring the success of outcomes. Many states are making changes to state guardianship laws to include SDM options.

While some individuals may be able to use SDM, it is not a "one size fits all" alternative to court appointed guardianship. When people with I/DD and their families are presented with Supported Decision-Making, they should consider the following:

- The Developmental Disabilities Assistance and Bill of Rights Act (DD Act) states: "individuals with developmental disabilities and their families are the primary decisionmakers regarding the services and supports such individuals and their families receive and play decision-making roles in policies and programs that affect the lives of such individuals and their families." -DD Act, 42 U.S.C. 15001(c)(3)(2000)
- Is the individual prepared to take on the responsibility of Supported Decision-Making?
- Is the individual's support group prepared to address the changing needs of the individual over the course of their lifetime?
- How will you maintain and ensure a consistent team of advisors?
- How do you reconcile the "Right to Fail" with the safety and comfort of the individual?
- How do you determine if Supported Decision Making is not working and legal guardianship would be appropriate?

You and your loved-ones with I/DD have the right to decide what is best for your unique situation, based on individual need. Take your time in making any major decisions regarding guardianship. Remember to always protect your right to guardianship by staying in compliance with all legal requirements and court-required documentation.

Please note: Your membership renewal date is listed at the bottom of the address label on the back page of this issue of The Voice.

VOR at the American Health Care Association's 2019 Conference, October, 2019

Last October, VOR's Rita Hoover and Hugo Dwyer attended the Annual Convention of the American Health Care Association (AHCA) in Orlando. We attended sessions for I/DD providers focusing on topics on leadership, recruitment of DSPs, encouraging the hiring of more foreign-born workers as DSPs, and ethics issues facing providers and caregivers. We also met with vendors of products services designed for individuals with I/DD and their caregivers, and we met some very nice, very dedicated people from across the country.



The keynote speaker at the event was Commander Kirk Lippold, USN (Retired), who had been the commanding officer of the USS Cole when the ship was attacked and bombed by al-Qaeda terrorists on October 12, 2000, killing 17 U.S. sailors. Commander Lippold used his experience with the attack to describe the privilege and burden of leadership, and to illustrate how leaders and members work best together when everyone has a sense of personal accountability for his or her role in the operation of an organization and the implementation of its mission.

VOR's 2019 Winter Fundraising Campaign

Every year, we reach out to members and non-members, families and family groups, caregivers and those who benefit from the care they so selflessly give, to ask for donations to sustain our activities throughout the coming year.

***VOR relies on donations from families like yours
to help us to give a voice to families like yours.
It's just that simple.***

VOR - A VOICE OF REASON

To become a member, or to donate to VOR, please fill out the form on the back of this newsletter, or go to www.vor.net to fill out an online form.

Thank you for your support!

Setting Up a Crowd Funding Page to Help Cover Costs for the VOR Annual Meeting in June

We hope that all of our members will consider coming to D.C. for our Annual Meeting and Legislative Initiative in June. We realize that the cost of the hotel, transportation to D.C. and back, and expenses during the trip can add up to a pretty penny.



There are several crowdfunding sites to choose from. Two of the best known are **GoFundMe** and **Fundly**. VOR's Liz Belile chose **Fundly** for her campaign last year, and she enthusiastically recommends it. She linked it to her Facebook account for better visibility.



***Several of our members have set up crowd funding pages online to help cover their costs.
It's not too early to start yours now!***

To sign up, you will need to use an email address that you use regularly. You can also use your Facebook to create an account, as Liz did. You will need to set a goal amount for how much you are hoping to raise. You may raise funds as an individual or as a team, as Liz did with her friends from Texas. Guesstimate the airfare, hotel costs, and other expenses. You may revise these costs later, if necessary. Then write your story. A great story will be open and descriptive, and include a bit about who you are, what you're raising funds for, and how the money will be spent. Be sure to emphasize that you want to give a voice to your loved one with I/DD in the halls of Congress!

For more information, you may go to:

Fundly: <https://fundly.com>

GoFundMe: <https://www.gofundme.com>

To view Liz Belile's page, go to: <https://fundly.com/dc-advocacy-trip>

We have recently updated our YouTube page, and we would like to post videos of our members and their loved ones with I/DD. We would be happy to edit your raw camera or smartphone video into a web-friendly presentation. VOR appreciates being able to celebrate your child/ward and his/her life. Below are some tips to help you make a better video:

LIGHT YOUR VIDEO - Your phone footage will look best when you shoot your video in natural light or very close to a window. Light will give you a picture that is nice and clear. If you move away from the window, your videos will look grainy (like in an old photograph). Do your best to record your videos in a well-lit area.

CLEAN YOUR CAMERA LENS REGULARLY - If your lens is dirty, it will produce a blurry video. If the lens is dirty, carefully clean it with a microfiber cloth.

SHOOT HORIZONTAL (LANDSCAPE MODE) - Be sure to orient your phone horizontally. News footage is recorded horizontally. If you record in portrait mode the video will have black borders in the final production. And don't forget that your TV and Computer Monitor sit horizontally and not vertical. Be sure you're holding the phone horizontally for each clip. This will make editing them easier.

KEEP IT STEADY BY USING BOTH HANDS - Always have two hands on the phone. Using two hands produces steadier footage and decreases chances of creating video with a wavy effect.

VIDEO RESOLUTION - Before taking a video on your phone, set the resolution. Video resolution refers to how large your movie will be. Older phones can record at 720p, 1080p and newer ones can record at 4K. For the absolute best video image quality, 4K resolution is the best choice but takes up the most space in your phone's memory storage.

DOUBLE CHECK THE FRAME RATE - Older phones can shoot video at 24, 30 or 60fps (frames per second). Since you are recording for YouTube or Facebook, 30fps is fine. 60fps is great for recording activities like sports, or something with lots of motion. In good lighting, 60 fps will make your video sharper and smoother, when taking action shots.

DON'T USE THE ZOOM CAPABILITY - The zoom on your phone is digital zoom, not optical zoom, which is not good for detail or image quality. Using it will likely make your video look grainy. Unless you have the iPhone 7 Plus camera or newer, zooming in on a phone will simply enlarge the image -- it won't get you closer to what you're filming -- so it'll make your final video blurry-looking. Instead, physically move your filming setup closer to your subject to eliminate the need to zoom in.

TURN OFF NOTIFICATIONS - A phone feature that could interrupt your filming is when your device receives notifications. Before you start filming, set your phone to DO NOT DISTURB mode to keep notifications going in the background so you can film uninterrupted. Swipe up on your phone and tap the crescent moon icon to put your phone in DO NOT DISTURB mode, and tap it again when you're done to return your phone to normal settings.

CHECK TO MAKE SURE THE PHONE'S BATTERY IS FULLY CHARGED BEFORE RECORDING - A partly charged phone can't handle the task of recording for an extended period of time. So be warned. The battery on the phone will drain very quickly. If you don't want to rely on your phone's internal battery your best option is to plug it into an outlet or use a battery pack.

MAKE SURE YOUR PHONE HAS ENOUGH STORAGE SPACE - If your phone doesn't have enough storage space you will get a notification that your phone does not have the space to record a video. Keep an eye on how much storage you have on your phone while shooting so you don't run out. Have a backup storage plan for important videos, like iCloud or Google Photos (free app).

AFTER YOU TAKE YOUR VIDEOS - You may email rebjapko@gmail.com the video file for post-production and editing but please be aware that google mail file attachment size limit is 25MB. If your video files are larger than 25 MB, then use this website <https://wetransfer.com/> to send files up to 2 GB for free to the email address above.

VOR reserves the right to determine whether or not your video is acceptable for posting on our page.

Currently featured on our page are clips of testimony from the hearings in Pennsylvania, personal stories from some of our members, Public Service Announcements from our members in Arkansas, and the presentations that were made at our 2019 Annual Meeting in Washington, D.C.

We hope you will enjoy them, and we hope you will subscribe. As soon as we get 100 subscribers, we will qualify for a nice, simple, easy to remember web address. Until then, we have a long, complicated, "who can remember that?" address:

<https://www.youtube.com/channel/UCogRUQSpvAHqeh5vLXy8rA>



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



Save the Date!
VOR's Annual Meeting & Legislative Initiative
Hyatt Regency Capitol Hill - Washington, D.C.
June 6 – 10, 2020

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

Membership / Contribution Form

VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007 Fax:
877-866-8377 or donate online @ <http://www.vor.net/get-involved>

Thank you for your dues and contributions!

I would like to give a gift membership to:

NAME _____

NAME _____

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CITY _____ STATE _____ ZIP _____

CITY _____ STATE _____ ZIP _____

TELEPHONE _____ FAX _____

TELEPHONE _____ FAX _____

EMAIL _____

EMAIL _____

☐ **MY CONTACT INFORMATION HAS CHANGED**

☐ **\$45 per year per individual;**

☐ **\$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: \$ _____**

☐ **I would like to make an additional donation to support VOR. An additional gift is enclosed for:**

☐ **\$2,500** ☐ **\$1,000** ☐ **\$500** ☐ **\$250** ☐ **\$100** ☐ **\$50** ☐ **Other \$ _____**

Make checks payable to VOR, or use your credit card: ☐ Visa ☐ MasterCard ☐ Discover

Card Number: _____ **Expires:** _____ / _____ **CVC (3-Digit Security Code):** _____

Signature: _____

If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information. If you have included VOR in your estate planning, or establish a memorial fund, please contact us. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or hdwyer@vor.net.

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**To make a memorial or honorary donation, please
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