VOR
the Voice
news and Views of VOR Supporters

Autumn, 2025

Greetings from VOR's President and Executive Director

This issue of the VOR Voice is a catch-up of our work for the last several months most notably our Legislative Initiative in May and our Annual Membership Meeting in June. As always, we continue work with like-minded organizations to improve services for people with I/DD and autism (ID/A) and to support a full range of residential options and employment opportunities. We continue to work to support 14(c) programs and facility-based work programs, to support the workforce of Direct Support Professionals (DSPs) that care for our family members with ID/A, and to eliminate the Settings Rule, which seriously restricts the development of innovative settings for residential treatment and care. We have created a new committee to work on the problem of a cohort of individuals who have fallen through the cracks of the system – those with co-occurring diagnoses of intellectual disabilities and severe mental illnesses (ID/SMI).

For the first half of this year, most of our advocacy has been directed at the legislative activity of the 119th Congress, and the "One Big Beautiful Bill Act" (OBBBA, or H.R.1), focusing on the drastic cuts to Medicaid proposed in the bill. With the current shortages in DSPs, and the increasing waitlist for services across the country, VOR is concerned that any cuts to Medicaid will negatively affect people with ID/A and their families.

One of the most difficult aspects of our advocacy has always been to separate politics from policy. As our political landscape has become more partisan, many pieces of legislation have come to be associated with one political party or the other, and many bills garner the strong support from one side of the aisle and strong opposition from the other. We do not subscribe to such partisanship. VOR's commitment is to our families and their loved ones. Our guiding principle in evaluating any legislation has always been our mission statement. "VOR supports high-quality care and human rights for ***all*** people with intellectual and developmental disabilities and autism." We advocate for a full range of residential settings and employment opportunities for people with I/DD and autism, and we support appropriate funding for the services upon which they depend.

VOR continues to monitor all bills introduced in Congress and to look for individual bills to support and oppose, based on our mission and our principles. We look closely at the bill language, and collaborate with policy specialists and like-minded organizations to determine their effect on our families and on the needs of the entire ID/A population. We continue to look for champions on Capitol Hill and in our Statehouses who understand the needs of our loved ones, and work to establish relationships.

We work extremely hard to keep our mission alive. You can see this on the following pages. We work to keep expenses to a minimum yet focus our resources on where they will be most effective. However, we cannot survive without donations from our members and friends like you. We depend completely on your generosity and must humbly ask again for your support. Please consider, once again to stay a dues-paying member and to continue to contribute generously to VOR. We cannot do this without you!

We are deeply grateful for all your gifts, and for your ongoing support.

Thank you,

Joanne St. Amand
Joanne St. Amand, President

Hugo Dwyer
Hugo Dwyer – Executive Director

VOR Monthly Giving Opportunities!

Monthly giving helps you make a larger gift over time and it's a safe and reliable way to give!
Monthly giving helps VOR to enhance and continue the good work we do protecting all people with I/DD.
Please consider a monthly gift.
Signing up is easy!!
Just fill out the form found on the back of the newsletter and mail, fax or email it to us.

VOR Legislative Initiative 2025

Last May, several members of VOR met in the nation's capital to speak with congressional staffers and federal regulatory agencies to discuss issues that concern families of people with I/DD and autism. Conference attendees make appointments with congressional staff a few weeks before the meetings, often sending materials a few days in advance to allow staffers to better prepare for our visits. A core group of attendees are selected to meet with lawyers from the Department of Justice's Office of Civil Rights (DOJ), and another group meets with the Administration for Community Living (ACL), Office of Civil Rights (OCR). Both of these agencies exist within the Department of Health and Human Services (HHS), ostensibly representing people with intellectual disabilities and the aging community.

Department of Justice

Our first meeting was on Monday, May 12, with the DOJ. We had confirmed the meeting on the previous Thursday; however, due to a round of federal employee layoffs at least two staff we have met with over these years were no longer with the agency when our meeting occurred. Despite the subdued and somewhat cautious atmosphere of the meeting, we stayed on course and followed our agenda to speak about the unfavorable consequences of many of DOJ's past actions.

VOR's Hugo Dwyer, Katrina Robertson, Rita Winkeler, DOJ's James Fletcher, Benjamin Tayloe, and Victoria Thomas, VOR's Casey Henry and Peter Kinzler.

Through the course of the meeting, we spoke of our concerns for the DOJ's ongoing actions against ICFs and the damage that they had done in the name of promoting "community living for all". We asked why, when there is so much abuse and neglect throughout the DD System, they rarely take action against large corporate providers in the Home and Community-Based Services (HCBS) silo, focusing almost exclusively on state-operated Intermediate Care Facilities (ICFs). As usual, they replied that they are mandated under the Civil Rights of Institutionalized Persons Act (CRIPA), and there is no similar mandate for them to investigate abuse and neglect in HCBS' smaller group homes. We went on to discuss their track record of bad outcomes, including deaths, that resulted from their actions in states like Georgia, Virginia, and Iowa, and as usual, they replied that those were not their responsibility, that these outcomes were the fault of the state governors and legislators and Departments of Disability Services that poorly responded to DOJ's reports of CRIPA violations.

But then they added that they might not have the same mandate, or the same resources this year under the new administration. The new Attorney General has different priorities, and those might not include any actions on behalf of, or interfering with, the best interests of people with I/DD and autism. Confirming this division's mandate and maintaining open lines of communication is important to ensure staff recognize both the immediate connection of their work to our community and to the broader and longer-term outcomes that are tied to their decisions. Further, Members of Congress and their staff expect advocates to work with administration staff to prevent duplicative laws from being passed, so it overlaps with our work on Capitol Hill

Administration for Community Living

On Tuesday morning, a group of us met with members of the ACL. Though still in their same offices as in previous years, ACL and thirteen other agencies had just been folded into the body of HHS following a restructuring of agency by the President. Mary Lazare is the head of ACL under the current administration, and she has worked in the disability space for decades. After exchanging introductions, we opened up a discussion of possible changes to disability policy. We expressed our hope that ACL's new position within HHS might lead to their advocating for *all* people with I/DD and autism and a *full* continuum of care, and not just representing people receiving services under HCBS while supporting policies that excluded

ICFs as part of a diverse range of residential treatment options. Without outright saying ‘no’, it appeared as though some members of the ACL would have been more comfortable sticking with their previous policies. Nonetheless, Deputy Administrator Lazare seemed more open to our position, and asked good questions as to what this might mean for our families. We went on to discuss our concerns with State Protection and Advocacy Agencies (P&As), and the fact that they fail to protect people while they focus their resources on forcing the closure of ICFs as the best way to promote the ideals of community living. P&As receive hundreds of millions of dollars, channeled through the ACL, and are rarely held to account by those who provide the funding. They are part of an untethered industry known as the National Disability Rights Network, that receives its funding through federal grants, primarily from the Protection and Advocacy P&A Systems Programs, such as the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program and the Protection and Advocacy for Individual Rights (PAIR) program. They then use some of these funds to lobby for more funding for these programs. We asked that HHS re-establish the marching orders for P&A to protect *all* people with disabilities, regardless of their degree of disability, the type of services they receive, the type of residence in which they live, or the funding stream within CMS that provides for their care. We asked that they instruct P&As to cease advocating against one ideology or another and focus on people, not on “community living”. Again, the members of the ACL appeared reluctant to change their outlook, even though they were no longer independent of HHS and are now the only agency within HHS that represents people with I/DD and autism.

Many of the same troublemakers who met with the DOJ waiting to meet with members of the ACL.

We also spoke about our efforts to work with the Link Center to try to find solutions for people who have co-occurring diagnoses of intellectual disabilities and severe mental illnesses. We had become aware of the Link Center at the last meeting of the President’s Committee for People with Intellectual Disabilities (PCPID). We asked that one of the people in our group be asked to sit on the PCPID next year, to which they replied that they do not choose the members of the committee, nor did they think it likely that there would be another meeting of the PCPID in the future.As an aside, VOR has engaged with the Link Center several times over the past year and found them to be open to sharing state level successes. You may have noticed them referenced in our emails. Please reach out if you would like additional information on our work with them.

Our Agenda for Meetings in Congressional Offices

While the above meetings set the stage for our fly-in, the most important part of VOR’s Annual Legislative Initiative has always been our outreach to Members of Congress and their Health staff. This year, our outreach was centered around the severe cuts to Medicaid funding as proposed by the President in his One Big Beautiful Bill Act (the OBBBA), which was being deliberated in Congress as H.R.1. While a few other ID/A advocacy groups had taken the position that *some* cuts were acceptable, as long as no cuts were made to services for people with I/DD and autism, we stood firm that *no* cuts were acceptable.

Some Members of Congress were supporting $1 trillion in cuts to Medicaid, claiming it was only going to eliminate waste, abuse and fraud within the Medicaid system. When the Congressional Budget Office (CBS) scored the bill, they estimated that waste, abuse, and fraud only amounted to about 1/3 of the $1 trillion. The rest of the cuts did not meet that criteria. In addition, we understood that while Congress was making those cuts, the individual states would have to take on the responsibility of determining how to allocate the drastically reduced amounts they would be receiving. We could not in good conscience say that *anything* in these cuts was acceptable. We know from experience that when broad cuts like these are enacted, there will always be ripple effects and unintended consequences. Those consequences could close hospitals that our loved ones rely upon. They could diminish the DSP workforce. They could take money that family caregivers rely upon to look after their loved ones at home, and they could result in the closing of group homes, skilled nursing facilities (SNFs) and ICFs. We have all seen that when there are such unintended consequences, they can prove fatal for the most vulnerable.

To prepare for our presentations with congressional staff, our conference participants learned about provider taxes, state directed payments, the Federal Medical Assistance Percentage (FMAP), state grants, and other ways in which funding for Medicaid might be cut. We discussed how Medicaid cuts would affect state budgets, and how governors would have to re-allocate resources cut from HCBS funding, supplemental nutrition programs for children and seniors (SNAP), hospitals, and programs supporting family caregivers. We learned that the proposed work requirements could result in family caregivers losing the funding they rely upon to look after loved one. We learned about the increased burden placed on states to report more frequently to the federal government about Medicaid recipients, and how people entitled to Medicaid benefits could lose those benefits through paperwork and bureaucratic errors. VOR's team of advocates became stellar, expert messengers on behalf of our friends and families!

Meetings with Members of Congress and Congressional Staff

VOR's Louisiana team: Michael and Sue Yacovissi, Casey Henry, Terry Lafleur, and Anne Schouest meet with Sen. Bill Cassidy's Senior Policy Advisor Ron Anderson (center)

Overall, our meetings went well. The general format for these meetings is simple. We sit down with staffers and ask them, "Do you have any family members with I/DD or autism, or do you know anyone with I/DD or autism?" They reply, yes or no, usually with a short description of a family member or someone who lives in their neighborhood, and we show them pictures to introduce them to our family members with I/DD. Then they typically ask us what our concerns are, and how they might help us. We describe the challenges our families face in finding appropriate care, in preserving the ICF system as a safety net, in hiring a well-trained, and well-compensated workforce of direct support professionals, in supporting a wide array of meaningful daily activities, ranging from day programs to sheltered workshops to competitive employment. We talk about the true meaning of Olmstead, and the need for a full continuum of care for this diverse population.

For several of our initiative participants, this year followed the pattern described above. Other participants felt that some staffers were more concerned with their presenting talking points for the OBBBA than in listening to our concerns about the bill. They were told that the bill was fixing the system, and that none of the cuts were intended to hurt the vulnerable individuals who truly rely on Medicaid. The lowered reimbursements that states would receive as the result of caps on provider taxes was explained as a correction, not a cut. Our questions about what safeguards were in place to make sure that our families wouldn't be burdened by increased paperwork, or lose services through bureaucratic errors, often wen unanswered. There was no acknowledgement of the likelihood of ripple effects and unintended consequences. Some staffers insisted that the cuts being made by the President and Congress were measured and responsible, intended to reduce only waste, abuse, and fraud, and that Congress couldn't be held responsible for any consequences that might arise from how they were to be carried out by individual states.

VOR's Katrina Robertson and Kimberly Dodd present a plaque honoring Senator Tom Cotton from their Family & Friends Association

Some people felt their voices were being heard on Capitol Hill, others did not. Nonetheless, we all agreed that the Legislative Initiative is still our most effective outreach, and most of us resolved to return to D.C. next May, to continue VOR's advocacy. Even when staff does not indicate a change in position based on our information and stories, our presence matters. Staffers often work for multiple Members of Congress or at a federal agency, and other opportunities to support our priorities may occur on down the road.

Top Left: Roslyn and David Leehey with staff from Rep. Mary Miller of Illinois

Top Right: Conference participants gather for an Informal debriefing session (and pizza) after Day One meetings.

Center Left: VOR President Joanne St. Amand and Sam Friedman meet with staff from New Jersey Rep. LaMonica McIver

Center Right: A taste of New Orleans in D.C. with Ann Schouest, Terry Lafleur, Louisiana Rep. Troy Carter, and Casey Henry

Bottom Left: Massachusetts' Marsha Hunt and Irene Tanzman meet with Rep. Derrick Van Orden of Wisconsin

Note: One VOR member from Louisiana who had always wanted to attend our fly-in wasn't available to go in May. Brenda Turnage had been the Treasurer of Pinecrest Parents Association for many years. So when she was ready, Terry Lafleur and Casey Henry made her wish come true.

My Legislative Fly-in

By Brenda Turnage

I went to Washington, D.C. to talk with our Representatives & Senators with Terry Lafleur & Casey Henry about cuts to Medicaid with the passing of the "Big Beautiful Bill" the first week in July.

My brother lived at Pinecrest for 55 years. He was 13 when he went there.

Pinecrest was his home & he had his parent's home too. Pinecrest found him jobs to do to earn a little money. He had almost every job at Pinecrest, because he usually broke the machinery. He worked every day until he "retired". He had the IQ of a 3-5 yr. old, but he had the social IQ of a 23-year-old. He was involved with whatever the staff was concerned about: politics, pay raises, days off & days on. He could never have lived in a group home, because he had to walk & go see everybody. He would go see his friends at the hospital, go to the canteen, and he would visit with the staff in different buildings. He was quite special!

About my visit to Washington. I was very impressed with the majority of the aides of the Senators & the House members. With the exception of one aide, they all took rigorous notes on our comments. We were assured that there would be no action taken until 2026 or 2028 with Medicaid. Also, they all said that their "bosses" would not take away our needed Medicaid for Pinecrest.

I fell it was most beneficial to go and speak with our congressmen and tell them our stories. They appeared to listen.

VOR Voice Award, 2025

At our Annual Membership Meeting in July, the Board of Directors awarded this year's Voice Award to Katrina Robertson, for her work in passing legislation in Arkansas to hold her state's Protection and Advocacy Group, Disability Rights Arkansas (DRA), to account for its activities and its use of the resources allocated to it annually by the Administration for Community Living. This was a remarkable achievement. Over the course of a few months, Katrina worked with State Representative Jack Ladyman to draft a bill and bring it before the State Legislature. She enlisted the aid of other families and ICF family organizations across the state to help. Despite a flood of opposition from DRA, the bill passed into law during the session.

We are very proud to award Katrina Robertson the VOR Voice Award for 2025!

VOR's 2025-2026 Board of Directors

This spring, VOR members voted to appoint Louisiana's Casey Henry to the Board of Directors, and to renew 3-year terms for Iowa's Sybil Finken and New Jersey's Sam Friedman. At our Board Meeting in July, we appointed the officers for the fiscal year ending on June 30, 2026.

Officers:

President – Joanne St. Amand (NJ)
First Vice President – Terry Lafleur (LA)
Second Vice President – Mary Vitale (MO)
Secretary – Rita Winkeler (IL)
Treasurer – Sam Friedman (NJ)

Directors:

Ronald Coleman (SC)
Sybil Finken (IA)
Casey Henry (LA)
Ann Knighton (GA)

Executive Director - Hugo Dwyer (NY) – (Ex Officio member of the Board of Directors)

VOR's 2025 LEGISLATIVE INITIATIVE SPONSORS

Platinum - $ 2,500

NJ Association for
Individuals with Intellectual Disabilities
Steve Bernard & Michelle Sullivan
Micki & Lanny Edelsohn
Parents/Friends of Ludeman Center
Ms. Lynn A. Royal

Gold - $1,000

Dr. Ronald and Caryn H. Miles
Mary Reese

Silver - $ 500

Bellefontaine Habilitation Center Parents Assn.
Katrina Robertson
Mark Engberg

Bronze - $ 250

Rita & Barry Altman
Cynthia Gaillard
Roslyn & David Leehey
Mary & Steve Vitale

Advocacy Heroes - $ 100

Harris Capps
Jill Clayton
Troyer

Friends & Families

Donna Ball
Marsha Hunt
Terry Lafleur
Mrs. Juliana Powers
Sue Von Dohlen

We would like to thank the individuals, families, and organizations that contributed to support our advocacy this year.

Following Up On Medicaid Cuts: Next Steps for Advocates

As our readers well know, our efforts to prevent the 119th Congress from making drastic cuts to Medicaid programs bore no fruit. The President signed his One Big Beautiful Bill Act into law on July 4, 2025, complete with nearly $1 Trillion in cuts to Medicaid over the next ten years. The majority of the cuts aren't scheduled to begin until after next year's mid-term elections, but many states are cutting back on programs and several hospitals and HCBS providers have already projected that they will be closing facilities in the year ahead.

While those members of Congress who supported these cuts insisted that people with I/DD would not be affected, we advise our members to remain vigilant. Speak with your providers about their plans for the future of your loved one's facility. Call your state DD Services Director's office and make sure you understand what changes are being made to services in your state. Call your state legislators and your governor and let them know how important continued funding for your family member's services are. Call them again. And again. Make sure your elected officials know you by name.

Fill out any and all paperwork thoroughly. The new law has doubled the amount of paperwork required, and lessened the number of people who review it. One error can mean your loved one's services are suspended for the next 6 months.

If you are a family caregiver, you may be about to lose many of the supports that have helped you care for your loved ones at home. You may lose the funding that has paid you for being a caregiver to your family member. You may even have to meet the work requirements provisions in the bill that have been included as a way to rid the Medicaid programs of people who commit 'waste, abuse, and fraud'.

So be pro-active in all you do and take nothing for granted. And most of all:

<u>VOTE</u>

Vote as though your loved one's life depends upon it.

What are Provider Taxes, and What Does It Mean When Congress Says It Won't Cut Provider Taxes for Intermediate Care Facilities?

Every state except Alaska charges taxes to providers of Medicaid Services. These taxes are passed on as part of the total that the federal government bases their payments to the state each year for Medicaid. In the One Big Beautiful Bill Act, Congress cut provider tax rates for most HCBS services, but not for Intermediate Care or Skilled Nursing Facilities.

But does that mean that ICFs and SNF's are safe from the Medicaid cuts in the OBBBA? **NO!**

Why? Because while Congress is determining how much to cut the total amount paid to states, they are not responsible for how the lessened appropriations will be spent. It's up to your governor or state legislators to determine how to allocate the reduced. Your state may decide to close an ICF or a SNF in order to compensate for the losses to HCBS services or the SNAP programs that feed children and the elderly. Or they may have to close a hospital that provides for our folks when they need hospital services. They may reallocate the state's entire budget, including new roads, schools, or infrastructure - or repairing existing services - as a way to cover the hundreds of millions of dollars cut from Medicaid. Or, in some states, the billions of dollars.

As states re-allocate funds, there is no guarantee that ICFs will receive the same amount of funding next year as they received last year. The statement that "No cuts to provider taxes for ICFs will protect ICFs" is misleading at best.

Celebrating the 60th Anniversary of Medicaid

July 30, 2025 marked the 60th Anniversary of Medicaid and Medicare. These two vital health programs were signed into law by President Lyndon B. Johnson, establishing a safety net for millions of Americans. The programs have proven to be especially significant in providing for the health and safety of people with intellectual and developmental disabilities. Without the movement that created these programs, there probably would never have been an Americans with Disabilities Act, an Olmstead Decision, or the development of Intermediate Care Facilities and Home- and Community-Based Services as we know them. Our families have come to rely on these programs. Many of our beloved family members with I/DD and autism would not be alive today without them.

Passing Medicaid and Medicare in 1965 was not an easy process. There was great opposition from conservatives, who saw them as government overreach, from the American Medical Association, who saw them as the first step on the path to socialized medicine, and by many taxpayers, who saw them as Welfare programs. To people with disabilities, to people who were physically or medically unable to work, to people who could not work because they were caring for sick, elderly, or disabled family members 24/7, these programs have been a blessing.

Medicaid has proven to be one of the most effective and cost-efficient large-scale government programs of all time. According to the *National Health Law Program*, "*Medicaid has a lower cost per service provided than any other health insurance program, public or private. In one comparison, the costs to cover low-income adults through Medicaid was 45% less than covering a similar group through private Marketplace insurance. In that same study, average annual out-of-pocket expenses for enrollees were over 10 times lower in Medicaid ($45 vs. $569). Administrative costs are low, at just 3.9% of total Medicaid spending in 2023. Medicaid managed care plans have additional administrative expenses, but nearly all states require their Medicaid plans spend at least 85% of plan expenditures on covered services.*"[1]

Researchers at the Commonwealth Fund affirm that Medicaid makes up about a third of most states' budgets. Medicaid investment is shown to have a "multiplier effect," meaning that every dollar spent generates over a dollar's worth of economic activity. Medicaid drives employment in the health care sector; generates state and local tax revenue; and saves money for enrollees, allowing them to spend more on items other than health care.[1]

According to KFF, one in five Americans receive Medicaid. The program accounts for over 60% of all long-term care spending. Medicaid is extremely popular, with 77% of Americans holding a favorable view of the program – 87% of Democrats, and 63% of Republicans.[1]

Despite these facts, opposition to Medicaid has resurfaced in recent years. Eight years ago, in July of 2017, a similar proposal to cut Medicaid by $1.3 Trillion in the 115th Congress was narrowly defeated when nine senators crossed party lines and voted against the bill. This year, despite moral and ethical objections to Medicaid cuts in the OBBBA from several prominent members of the Senate, the bill passed strictly along party lines. This year, Politics won out over Policy.

Now, dampening our celebrations of 60 years or Medicaid, we are bearing witness to the most drastic cuts in the history of the program.

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[1] https://healthlaw.org/medicaid-is-even-leaner-as-accountability-improves

[2] https://www.commonwealthfund.org/publications/explainer/2025/may/how-does-medicaid-benefit-states

[3] https://www.kff.org/medicaid/10-things-to-know-about-medicaid/

Celebrating the 60th Anniversary of The Bellefontaine Rehabilitation Center Parent Association

By Mary Vitale

The importance and effectiveness of advocacy for individuals with intellectual and developmental disabilities by family organizations is being highlighted as the Bellefontaine Habilitation Center Parents Association celebrates 60 years of service.

The Bellefontaine Habilitation Center is a state operated intermediate care facility for individuals with intellectual disabilities in Missouri.

For 60 years the Parents Association has been vigilant in seeing that the intellectually disabled residents of the Bellefontaine Habilitation Center receive necessary services for their safety, health, and well-being. The organization has been continually active on the local, state and national level to give a voice to the residents who have no voice of their own. Over the years, major funding has been earned from the untiring work of the volunteers of the Hidden Treasure Thrift Shop.

These funds, along with donations and tributes from members and others, have been used to benefit the residents. Each year thousands of dollars from the Parents Association have provided an abundance of enjoyable extras for the residents. Also, to express appreciation to employees, the Parents Association has funded some the Employee Recognition activities.

It all began in 1965 with a group of 27 dedicated parents who developed plans to organize a Parents Association to work for better services and living conditions for the residents of the then St. Louis State School and Hospital (renamed Bellefontaine Habilitation Center). This organization of parents meant having the power to work for positive change with legislators and the Department of Mental Health administration.

Over the next few years, many other parents, relatives, guardians, and friends joined the Parents Association. They volunteered time, made donations, and began to help form public policy about the care of Missouri residents with an intellectual disability.

New admissions to any Missouri habilitation center were closed in 2012. To this day, the Parents Association is advocating to reopen admissions. BHC continues to serve current residents and also has 8 crisis beds for individuals needing temporary services until placement is found in the community.

The Parents Association continues to support residents by funding for extras such as: birthday cakes and gifts, Christmas gifts, holiday parties, holiday decorations, home décor, annual picnic, and staff appreciation. Education of legislators about the importance of the Bellefontaine Habilitation Center is ongoing.

All of these accomplishments were possible because families came together to support one another. They then acted to educate legislators, to communicate with state mental health officials and facility staff, and to encourage support from the general public.

For 60 years many devoted board members, committee members, and general members have given time and talent to the Parents Association to enable the association to be an influential leader concerning policies that affect the daily lives of residents.

Happy 60th Anniversary to the Bellefontaine Habilitation Center Parents Association.

The Importance of an ICF Family Association

Over the years, ICF Family groups have been a mainstay of VOR’s advocacy, and a force within each state to protect the rights of individuals with I/DD to have access to a full continuum of care. The Parents Association of the Bellefontaine Habilitation Center, above, is just one such group. There are dozens of others in most of the states that still have public ICFs. Over the years, our family organizations have stood up to the DOJ, to P&As, immediate closure to the sunsetting of the facilities through the prohibition of new admissions. Fighting a lawsuit from these groups can cost several hundred thousand dollars, further straining the financial resources of the families involved. The emotional toll these actions take on us can never be measured. Only by working together through a family organization can we raise enough money, will, and determination to overcome these calloused assaults on what our families know to be essential services.

In addition to the advocacy and legal defense, our ICF family groups have provided millions of dollars of additional supports to the residents. We cover costs of programs and services not provided by Medicaid dollars. We provide holiday parties and gifts, so that no individual feels left behind should they no longer have family who can be with them on these occasions. We organize off-campus trips for residents. We plant trees and buy picnic benches and support campus beautification projects. We engage the community around the ICF in on-site events, organized bake sales and carwashes, and create summer internships for high school students that help increase understanding of the needs and the value and the personhood of our loved ones.

Family groups support the DSPs and admin staff of the ICFs. We forge relationships with those who work most closely with their loved ones. We ask what the DSPs need to better. We augment their caregiving by hiring music therapists, art therapists, physical therapists, and behavioral services. Our presence on the campus and our positive interactions with staff serves to improve morale. Goodwill can never be underestimated. We also hold the admin and caregivers to account. Having members of the family group drop in from time to time is the best way to spot any possible incidents of abuse or neglect.

Belonging to a family group enriches us. It brings us closer to other families, and makes us understand that we are not alone. I well remember several conversations from 10 years ago with Jane Anthony, a VOR member and mom from Virginia. A DOJ action had recently resulted in the closing of the ICF where her son Jason had lived most of his life. He had been transferred to an HCBS group home. At the time, she had just dissolved the family group from her son’s center. She reflected on the fact that she felt disconnected. The group home was further away, she and Jason’s father were not able to visit as easily, and she didn’t know any of the other residents’ families. If she sensed something might be amiss at the home, she had no one to help her except the P&A or the local Arc, neither of whom spent much of their time or resources on individual problems at the group homes that they so actively advocated for. She felt alone. In the absence of a family group like the one at North Virginia Training Center, it seemed that there was no sense of community in the community.

Seth's Story Continues

By Sybil Finken

As many VOR members know, my son Seth was left devastatingly damaged from meningitis at age 7 months. Seth is now 46 years old, blind and deaf, non-ambulatory and non-communicative. He has a seizure disorder and requires 24/7 care for all his needs. Seth made his home on the campus of Glenwood Resource Center (GRC) for nearly 40 years. Suddenly, and with little warning, GRC was closed.* The 150 profoundly challenged individuals who made GRC their home were shuffled off to the other Iowa state facility and various private homes and group homes. Many have already died.

Seth's seizure disorder landed him in a Hospice house, part of the Glen Haven Village nursing facility in Glenwood, which is located on part of what was once the GRC campus. His health improved and he no longer needed hospice care. Seth was then moved to another cottage on the Glen Haven Village campus, which happened to be the very cottage in which he had grown up. After a period of adjustment, he settled into daily life and grew comfortable with the staff.

One year later... I received a call from the director of Glen Haven Village telling me that they would like to move Seth. It seems that Medicaid only pays for semi-private rooms. Seth has been living in a single room. Knowing how difficult any change or transition is for Seth, I inquired about keeping him in his original room. For $1000 per month, Seth could stay where he was. I told the director that I thought Seth had been through enough change and I would pay the $1000 per month out of pocket.

As a retired teacher, recently widowed, $1000 per month isn't an amount that I had planned for. I feel fortunate that, currently, I can make the payments and not have to make other unwanted changes in my life -- or in Seth's.

There are so many concerning parts of Seth's story. His illness, his disability, the closure of his home, and now his challenge with Medicaid funding. It seems that Seth has had one issue after another for his whole life. I hope that I will be able to cover Seth's expenses and help to make his life as comfortable as possible.

**DOJ entered a settlement agreement with the State of Iowa in December, 2022. Four months later, Governor Kim Reynolds reversed her promise to keep GRC open, and announced that she would close the center and use ARPA funds to move long-term residents to HCBS settings wherever possible, A small number of individuals were moved across the state to the last remaining ICF, or to nursing facilities. GRC was closed on June 30, 2024.*

Sybil Finken is a former President of VOR, and one of our original members.
This story is a follow-up to the article in the Winter, 2023 edition of the VOR Voice

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VOR SPOTLIGHT: Individuals with Co-occurring Intellectual Disabilities and Severe Mental Illnesses

Over the past year, VOR has been reaching out to learn, educate, and advocate on behalf of individuals with co-occurring diagnoses of Intellectual Disabilities and Severe Mental Illnesses (ID/SMI). This is a high acuity population who require specialized treatment. Most state Developmental Disability Service Administrations (DDS) have no provisions for people with I/DD with co-occurring mental illnesses. Conversely, most state Departments of Mental Health have no services for people with mental illnesses and I/DD. As a result, there are few appropriate long-term residential treatment options available for individuals who present with ID/SMI. Without such facilities, the fallback positions have been extended stay in hospitals or psychiatric hospitals, forensic facilities, and the prison system. Some states have moved a number of individuals to Intermediate Care Facilities, but ICFs are designed for a different population, and few have the resources to deal with more aggressive and violent clients. The only other options have been in-home care or a privately funded home, solutions that are both prohibitively expensive and unsustainable in the long-term.

We have recently assembled a committee to look into how we can bring awareness to this population, share successful models of treatment with other interested families, and speak with stakeholders at HHS, ACL. The Link Center, The National Association of State Directors of Developmental Disabilities Services (NASDDDS), and state legislators to increase services for this unseen and underserved cohort of the I/DD population. This November, we hope to send one of our members, Jill Clayton, to represent VOR at the NASDDDS Conference in Arizona. ***(Jill and her daughter Abby were featured in last fall's issue of the VOR Voice****)* The agenda for much of this conference centers around discussions for how best to serve the ID/SMI population.

If you or someone you know has a child or sibling who presents with ID/SMI, and you would like more information about VOR's efforts on their behalf, please contact Hugo Dwyer at *hdwyervor@gmail.com.*

All back issues of the VOR Voice are available on our website at www.vor.net

A Time for Unity and Understanding

In the months and years ahead, the disability community will be facing a drastic reduction in funding as a result of the One Big Beautiful Bill Act. Every state will see a different re-appropriation of funds to its safety net programs, including services to children, the elderly, and to the community individuals with I/DD and autism (ID/A).

It is our hope that these difficult times serve to bring I/D/A communities together, and that by joining together we can create a stronger voice, and help one another to find services and to cope through the problems that lie ahead.

At VOR we advocate for CHOICE. But what does that really mean? The first word that comes to mind is freedom. The second word, is responsibility. Because the freedom to make your own choices comes with the responsibility to accept the choices made by others, whether or not you yourself would have made the same choice. Acceptance alone is not enough. Choice requires understanding – understanding that each of us has very different challenges, and a different menu of options available to them. But acceptance and understanding are not enough. We need to support one another and support each other's choices.

The decisions that individuals with ID/A and their families have to make are not easy. We try to make informed choices and we anguish over whether or not we have made the right decision. And we live with the voices in our heads that say, "Have I made the right choice? Was this the best option?".

Individuals who choose self-direction and families who decide to care for their loved ones in their own home have no easier course than families who choose group homes or ICF care for their loved ones. It takes courage and strength to put together a supported decision-making plan and to advocate for one's own services on one's own terms. It takes resolve and a multitude of personal sacrifices to accommodate a family member with ID/A at home. It takes compassion to apply for guardianship for a loved one who cannot make life-sustaining choices for themselves. And it is heartbreaking to decide that your loved one will lead a better life with professional supports rather than those the family can provide. While we celebrate one person's opportunity to work in competitive, integrated employment, we must also celebrate someone who finds fulfillment in a sheltered workshop, or the joy that another individual experiences in their day program. VOR supports any and all meaningful daily activities, as long as they bring value to the lives of those who participate.

There is no single solution to *anyone's* life choices, whether there is ID/A involved or not. And no doubt, with the approaching drastic cuts in Medicaid, the choices we will have to make in the future will be even more challenging. But we as a community will benefit from understanding and supporting one another's choices, whatever they may be, and in helping one another navigate the challenges that arise from the cuts to Medicaid funding that have been passed into law.

The Saving Wrentham and Hogan Alliance

Q. When is an ICF Family Organization not an ICF Family Organization?

A. When the members of the organization are on the outside, trying to get in.

The Saving Wrentham and Hogan Alliance is such an organization. Recently established by Irene Tanzman, the group consists of families who advocate for Massachusetts' last two state-operated intermediate care facilities to expand their capacity and re-open to accept new admissions. They want to change the model of the facilities, to build housing on the grounds for families who wish to live near their loved ones and for staff. They want to build a more expansive community.

When Choice is Denied, Discrimination Thrives.

The Alliance consists of families who feel their loved ones are not being well-served in HCBS settings, and would fare better with ICF-level care. It includes families whose loved ones currently reside in the Wrentham or Hogan facilities, who envision a better, more effective, more efficient, more interactive community for their loved ones. It includes a Direct Support Professional and the Director of AFCSME Local 93, the union that represents the DSP workforce at Wrentham and Hogan. Finally, the Alliance also includes advocates from state and national organizations, like Dave Kassel from COFAR, David Schildmeier of the Massachusetts Nurses Association, Jackie Kancir of the National Council for Severe Autism, and Hugo Dwyer from VOR – A Voice of Reason.

The Alliance's vision includes:

- Expanding Admissions
- Intergenerational Housing on the Wrentham Campus to ensure that elderly parents may live close to their adult children with I/DD in a community that can also address *their* needs
- A Robust Volunteer Operation to bridge generations of family members and members of the Community
- A Humane Emergency Stabilization Unit
- A Center for Trauma-Informed Research and Care
- A Teaching Hospital for IDD, Mental Health, Chronic Illness, and Sensory Care

If you would like to learn more about the Saving Wrentham and Hogan Alliance or see about making a contribution, please send a friendly email to: savingwrenthamhogan@yahoo.com
or visit them on Facebook at: https://www.facebook.com/groups/1293658201859475

VOR
A Voice Of Reason
Speaking Out for People with
Intellectual & Developmental Disabilities

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

VOR Podcasts!

VOR's Casey Henry and Brenna Redfearn have started a new series of podcasts to share with our families on our ***YouTube page***.

Their goal is to interview VOR members, Board members, DSPs, and maybe even some state legislators.

If you would like to share your story with Brenna and Casey, please email us at ***info@vor.net***

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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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.