VOR the Voice
news and Views of VOR Supporters

Spring, 2025

Greetings from VOR's President and Executive Director

Back to Capitol Hill!

VOR's Legislative Initiative

May 12 – 14, 2025

~~ Advocacy. It's not just talking the talk. It's walking the walk. ~~

Once again, we're off to Washington, D.C. to speak out about the needs of our families, and of our loved ones with intellectual and developmental disabilities and autism. Yes, we write emails, make phone calls, participate in webinars, and reach out in Zoom and Teams meetings. But there's nothing more effective than showing up, looking people in the eye, delivering our message, checking the body language of the people you're speaking with to see what parts of your message are working and which are falling flat, and adjusting accordingly to make someone understand how important these issues are to us. And for the hundreds of offices at which we can't get meetings, we will leave behind our folders and a business card and follow up by email.

This issue of the VOR Voice is all about advocacy. Past, present, and future. We thought it would be good for our members to hear from two of our seasoned veterans as well as two of our newer members. And we're not just talking about what we do by going to Capitol Hill. We're also talking about what **you** can do in your state capitol, and what **you** can do from home.

VOR mission has always been to give a voice to those who cannot speak for themselves. It's even been in our name, since our very inception, and it is in our name again today, when we call ourselves a Voice of Reason. We are not self-advocates. Self-advocates rarely speak on behalf of our loved ones. We must be the voice for our family members. And even though some members of our community don't speak for us, we must try to unite and speak for them. That is what Reason means: That we support CHOICE. We support the rights of individuals with I/DD and autism to make their own choices, and we support the rights of families and guardians to make those choices when their loved ones lack the capacity to make choices that promote their own health, safety, and well-being.

Advocating this year is more difficult than it ever has been. The new administration and the new congress have different priorities, placing tax cuts and spending cuts above the need to protect or reinvest in our long-term services and supports. Meanwhile, the political landscape keeps changing from one day to the next. It's hard to predict what will happen to Medicaid between now and May 12th. Will congress have already forced through a Reconciliation Bill that cuts $880 billion from Medicaid? Will they still be negotiating, or will they not yet have been able to pass anything? Can we work together with other ID/A advocates to create as strong a voice opposing cuts to Medicaid as the business community did in postponing and renegotiating the tariffs?

We don't know the answers to these questions. We just know what the outcomes will be if we don't show up and speak out. And we know that we need to avoid the polarizing politics and focus on our own stories and what we need to ensure the best outcomes for our loved ones. So call your members of Congress. Call your state representatives and senators. Go to your statehouse, and get your elected officials to recognize you when they see you in the halls. Get them to know you by name, and get them to know the names of your loved ones.

We work extremely hard to keep our mission alive. You can see this on the following pages. And we work to keep expenses to a minimum yet focus our resources on where they will do the most for our mission. 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 donating 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, VOR Board of Directors

Hugo Dwyer
Hugo Dwyer
Executive Director of VOR – A Voice of Reason

Because of You - By Tamie Hopp

Hugo recently reminded me that it has been 10 years since my last day as a VOR employee. Because we have been talking weekly for these 10 years, he recognizes that I have never really left VOR. What started out as my effort to ensure Hugo had what he need to start out strong and be successful for VOR, has led to a deeper friendship and mutual mentoring in advocacy and fundraising.

When I first left VOR, I worked for a university in an alumni and foundation role. For the past 6 years, however, I have been working for the Black Hills Works, an agency supporting nearly 600 people with disabilities in Rapid City, South Dakota. I serve the Foundation, helping to raise funds and awareness for Black Hills Works, which is really about celebrating the value that people with disabilities bring to all of us as our family members, friends, neighbors, coworkers, and volunteers.

For the past decade, VOR – and all of you – have remained in my heart. I'm indebted to each of you for the person and professional I have become. Even now, I have spent more of my formative professional years at VOR than anywhere else since. For nearly 20 years, from 1995 to 2015, I served VOR and learned from you.

In 2021, I spoke about my time at VOR, my gratitude, and what you taught me in a speech for Black Hills Leadership Development, titled "Unexpected Leadership: Recognizing Leadership in Yourself and Others":

> *"At the time I was hired by VOR, I was barely 25 years old with no real-life experience. I was still about a decade from having kids of my own, but I found myself in a role where parents across the country were trusting me to lead them and prepare them to talk with state and federal elected officials about the care that their family members required. They were fighting at the state and federal levels for the quality care that their family members needed.*
>
> *I don't think I appreciated the significance of my role, and the significance of the trust they put in me. They were desperate to protect and provide for their loved ones, many of whom were so fragile that it was a literally a life-or-death situation. These parents, who had a lifetime of experience raising and knowing their kids with profound disabilities, were the real experts."*

During my time in VOR, I had the pleasure of working with, and learning from, exceptional leaders. Some of you are still involved, after all these years, and in the past 10 years, new incredible advocates have joined the cause. It's remarkable –due to all of you – that the VOR remains in the fight.

AND WHO IS VOR? - VOR IS YOU!

Your voice, and your involvement, matters - especially when joined by me and others who embrace choice. Collectively, with VOR's good guidance, we make a difference.

- ***Because of you****, choice is the law and quality of care matters.*
- ***Because of you****, your family members have a voice in your state legislatures and Congress.*
- ***Because of you****, the notion that the people caring for your loved ones deserve adequate pay, certifications, professional designations, and a career ladder is gaining attention.*
- ***Because of you****, for 42 years, against all odds, VOR has been advocating for the highest quality care, human rights, and for families to have real choices in residential options for individuals with I/DD and autism – for many of those years, the only national organization doing so.*
- ***Because of your leadership in your own states and before Congress****, VOR remains a credible resource to families, elected officials, and officials weighing laws, regulations, and policy that will impact the quality of life of all people with intellectual and developmental disabilities.*

There is a direct throughline from the work I do now and the work I did for VOR. Because of the mentoring I received at VOR, and the important work we all did together, I know the importance of seeing and protecting human potential – and that comes down to providing high quality, highly individualized support and care.

As families and VOR advocates, just like the people with disabilities I know work with and for, you taught me so much about being humble but fierce in the face of injustice, and optimistic in the face of adversity.

Keep up the good fight! It's necessary and as my good friend, Ann Knighton, would always say: If not us, then who?

Ann and me

Dinner with Mary Reese and Jill Barker

It Mattered Then. It Matters Now.

By Peter Kinzler

In these times of ongoing attacks on ICFs and threatened deep cuts to Medicaid, it is tempting to feel helpless, to say my input doesn't make a difference. A brief examination of VOR's history and an awareness of how Congressional offices used to operate and still operate, even in today's bitterly divided Congress, puts the lie to that notion. Your input, particularly when targeted with the help of VOR, makes a difference.

A quick look back confirms this fact. In 1983, my son Jason, who has Angelman Syndrome, was an 8-year-old living happily at the Northern Virginia Training Center, a wonderful ICF. At the time, I was working for Senator Christopher J. Dodd (D-CT) when I learned that Senator John Chafee (R-RI) was planning hearings on a bill he was considering introducing to close all ICFs. I was able to secure the opportunity to testify at the hearing along with George O'Donnell, I believe. We were both to become active members of VOR and I still am (George died a number of years ago).

Our testimony showed that there was opposition to the idea. Then VOR, in its infancy, was able to marshal sufficient resources to encourage a counter Senate bill by Senator James Exon (D-NE) to improve the quality of ICFs. VOR also was able to secure legislative language in the House to protect individual and family choice that Rep. Henry Waxman (D-CA), the powerful chairman of the Health Subcommittee, included in the Development Disabilities Act. The lobbying that VOR spearheaded stopped the Chafee bill from becoming law and led to strong legislative and appropriations language reinforcing the Supreme Court's emphasis on choice.

Jason then…

VOR's success in securing these legislative successes were often the direct result of our members' connections with influential legislators, such as that of Polly Spare, VOR's first president, with Rep. Jim Greenwood (R-PA) and Mary McTernan, a later VOR president, with Rep. Barney Frank (D-MA). In addition, much of the early lobbying success was due to the efforts of Larry Innis, Tamie Hopp, and myself.

The various legislative efforts over many years slowed but did not stop the Department of Justice and Protection and Advocacy (P&A) from pursuing lawsuits to close large ICFs. They filed over 40 suits that led to the closure of the vast majority of large, state-operated ICFs. Still, VOR's effective advocacy is responsible for not only keeping many large and small ICFs open but also for encouraging DOJ to include many provisions in settlement agreements to monitor the quality of care for those forced to leave ICFs.

All of which brings me back to my central point: **your advocacy makes a difference**. All Members of Congress' top priority is to get re-elected. They monitor carefully all constituent contacts, both with their offices in Washington, DC and with their state or district offices.

With regard to the present threat to Medicaid, while it was politically easy for Republicans in the Senate and House to pass budget resolutions calling for undefined large cuts in spending, these next few weeks are when the rubber hits the road. What specific areas will be cut and how will it be done? The reality is that the reduction goals cannot be met without large cut in Medicaid. Will Republicans have the votes to cut Medicaid and, if so, by how much and in what way?

and Jason now

Now is the time when the members have to decide what to do about Medicaid. So now is the time to contact your senator and representative and tell them about the importance of Medicaid for your loved one. Email, write and call them to let them know that the very existence of your loved one depends on Medicaid levels that assure qualified staff and facilities that are sufficiently funded to protect their care.

More Pictures from Tamie – VOR's Legislative Initiative from 2015

(L Top) **Peter Kinzler and me**

(L Bottom) **Linda Scherer and Mary Reese meeting with a Maryland Health Legislative Assistant (My apologies to the staffer for having misplaced her name!)**

(Center) **– Iowans Sybil Finken and Marilyn Straw, taking VOR's message to Capitol Hill.**

(R) **– Rep. Donna Edwards of Maryland with Mary Reese and Larry Innis.**

Patience, Persistence, and Determination

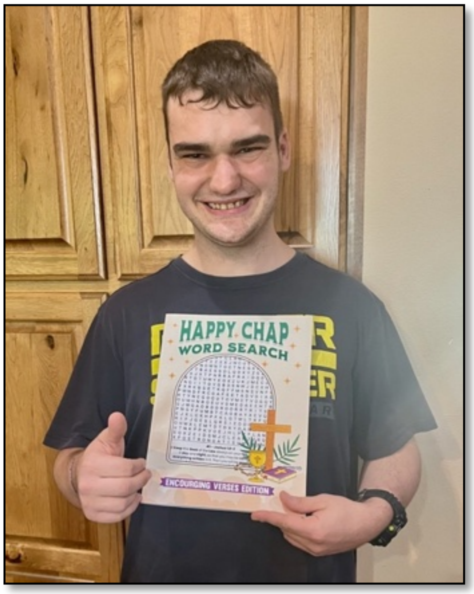
By Katrina Robertson

Last May, I traveled to Washington, DC, to start learning about advocacy work. At the time, I was blissfully unaware of the intricacies of politics. I didn't fully understand the structure, the process, or the many layers involved. But as I walked through those marble halls, everything began to shift. I listened to debates echoing through the corridors, watched young professionals in suits dart in and out of offices, heard bells ring as votes were cast and counted, and noticed the uniformed officials who carried themselves with unmistakable authority. Blacked-out SUVs lined the streets, and the entire place felt like a living, breathing machine.

For the first time, I began to genuinely respect our system of government. Flawed, yes—as all systems created by humans are—but also intricate, powerful, and ultimately dependable when the people *speak up*. Despite the chaos and the fast pace of change in today's political landscape, I left DC with a renewed sense of confidence in the process.

Next month, I'll be back, eager once again to witness democracy in action and to watch the system move forward as voices are heard.

Last May, I set out with a clear purpose: to learn how to advocate for individuals with the most profound disabilities—people like my son. When we adopted Noah at nine years old, we knew he had intellectual disabilities. Still, we were confident that, with the help of caregivers through waiver services and the unwavering support of our family, we could give him a life filled with as much independence and dignity as possible at home.



That dream ended in heartbreak.

Noah spent 45 agonizing days sedated on the floor of an emergency room, only to be transferred to jail. Every waiver provider had "fired" him – meaning that *they* were unable to meet his complex needs and unwilling to accept the liability he posed. In desperation, I searched for residential options. That's when I discovered that each state has a Protection and Advocacy (P&A) agency, federally mandated, to ensure individuals with disabilities receive proper care and are protected from neglect and abuse. In our state, that organization is Disability Rights Arkansas (DRA).

I made one phone call to DRA while Noah was in jail. It left me shaking with anger. Instead of offering tangible help, I was made to feel like I had failed—as though I had not tried hard enough to keep Noah "in the community," which, I was told, was the only way he could live with dignity. It was clear the person on the other end had no real understanding of what it takes to care for someone with profound intellectual disabilities and severe mental health challenges.

Eventually, Noah found placement in a state-run Intermediate Care Facility (ICF), and for the first time in a long time, he began to thrive. He had a job. He made friends. He had a girlfriend. He was supported by well-trained staff around the clock, people who could manage his behavior and keep everyone safe. He gained dignity—not by being forced into an unsupported community setting, but by being placed somewhere that could meet his needs with compassion and competence.

Still, that conversation with DRA stuck with me. I began researching them further and was disturbed to learn that this federally funded organization not only refuses to support congregate care settings like Noah's but actively works to dismantle them, including the very program that gave my son a job and a sense of purpose.

I was now on a mission. While in DC, I learned about recent laws in Ohio and North Carolina that called for regular hearings before their state legislators, holding their P&A's to account for their use of the funds allocated to them, and allowing the people of the state to testify about support given by their P&A , or to speak about the barriers to care set in their path. I told Hugo I planned to return to Arkansas and begin drafting a bill to spark change. He raised his eyebrows and said, "It's not that easy."

Challenge accepted.

As soon as I got home, I began reaching out to legislators. I knew Representative Jack Ladyman would be one of our strongest allies—his own son lives in one of our state's ICFs, so he understands firsthand the vital support they provide. With his help, we drafted a bill and started spreading the word to other Representatives and Senators. We weren't alone, other parent advocates across the state joined in, sharing their stories and building momentum.

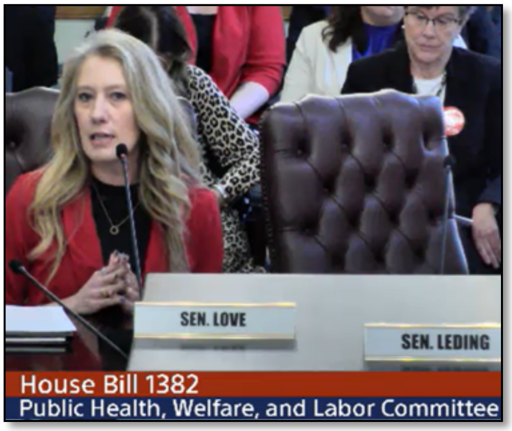
Once legislators heard our voices, most quickly got on board. Representative Ladyman agreed to sponsor the bill and moved it onto the agenda—but without notifying our parent group first. Within hours, Disability Rights Arkansas launched a campaign, flooding lawmakers with calls and spreading misinformation on social media, urging them to oppose the bill.

Representative Ladyman was stunned. He reached out to me and said, "I had no idea they would fight this so hard."

"Welcome to what we've been dealing with."

(Continued on following page)

To me, their fierce resistance to such a simple transparency measure was another glaring red flag about their true priorities. Why would a federally funded organization push back so strongly against being open with the very legislators, parents, and guardians they're meant to serve?



Now, less than a year later, the bill has passed both the House and the Senate—and on April 8, 2025, the Governor signed it into law, as Act 481*

Patience. Persistence. Determination.

I have all three in spades—especially when someone tells me I can't do something.

Here's the truth: I'm not extraordinary. I didn't do anything that any one of you couldn't do, too. What it *does* take is the courage to accept that not everyone will agree with you—and that's okay.

But never underestimate the power of a story—*your* story. Many of you carry experiences that others will never know about unless you choose to share them. And those stories? They have the power to move hearts, shift minds, and drive real change.

Many of you reading this carry the story of someone who cannot speak for themselves. That's true for me, too. My son, Noah, can't tell his own story—so it's my responsibility to be his voice. And I don't take that responsibility lightly.

Speak up. Share your story. Use it to make a difference.

* *Act 481 may be viewed at:* ***https://arkleg.state.ar.us/Bills/Detail?id=hb1382&ddBienniumSession=2025%2F2025R***

Advocating For Medical Research Funding

By Casey Henry

In March 2025, I had the privilege of traveling to Washington, D.C. to advocate for increased research funding for Tuberous Sclerosis Complex (TSC) and related disorders. This journey was deeply personal for me as my daughter, Katie, was diagnosed with TSC shortly after her birth in 2002. Reflecting on the advancements made over the past two decades, I am both heartened by the progress and reminded of the critical need for continued research.

TSC is a genetic disorder characterized by the growth of benign tumors in various organs, leading to a range of health challenges. Notably, it is among the leading genetic causes of epilepsy and autism spectrum disorder (ASD). Approximately 70% to 85% of individuals with TSC experience epilepsy, often manifesting in early childhood. Additionally, studies indicate that up to 50% of TSC patients are diagnosed with ASD.

The past two decades have seen significant strides in understanding and managing TSC. Research has elucidated the relationship between early onset seizures and the development of ASD in TSC patients, underscoring the importance of timely interventions. Advancements in genetic testing have facilitated earlier diagnoses, allowing for proactive management strategies that can improve quality of life.

Advocates for TSC Research w. Sen. John Kennedy

During my visit to the capital, I had the opportunity to meet with researchers, clinicians, and fellow advocates. Witnessing firsthand the dedication to unraveling the complexities of TSC was inspiring. Equally rewarding was observing the tangible outcomes of research: children born today benefit from a broader spectrum of therapeutic options, including targeted medications and individualized therapies, compared to when Katie was diagnosed.

However, our journey is far from complete. Despite our best effort to advocate and fight for critical government funding for these studies, we were unsuccessful. Earlier this year, funding for our division was cut by 55% across the board. Although this is devastating, we will continue to fight for funding to ensure all those who suffer from TSC have the best opportunity to live a life of health and wellness. My trip to Washington, D.C., reinforced the power of advocacy and the collective impact we can achieve. It is imperative that we persist in our endeavors, ensuring that research remains at the forefront of our mission to enhance the lives of individuals and families touched by TSC.

The intricate nature of TSC, with its overlapping manifestations of epilepsy, ASD, and other neuropsychiatric disorders, necessitates sustained research efforts. By continuing to explore the underlying mechanisms and potential treatments, we can aspire to offer those affected by TSC and related conditions a future filled with hope and improved well-being.

The State of Our Advocacy – April, 2025

This has been a challenging year for I/DD advocates. Everything, *literally everything*, has changed in for us within the federal government. In a few short weeks, our battles to preserve choice and protect ICFs from the one-size-fits-all policies of the Biden and Obama administrations seem like a distant memory. Now, we find ourselves fighting to preserve Medicaid, not only for people on the severe/profound end of the scale, but for every person with I/DD or autism, no matter where they are on the spectrum or where they live and receive services.

They say politics makes strange bedfellows, and it's true. We find ourselves siding with several groups that have opposed us in the past – including the Arc and self-advocacy groups like , who demand "No Cuts To Medicaid", while disagreeing with some of our usually dependable allies who are messaging that cutting some people out of Medicaid might strengthen the support for those who need it most.

Let's be honest. We all know that congress isn't really trying to improve Medicaid by eliminating fraud, waste and abuse. They are trying to arrive at a number, $880 Billion, in order to pass a reconciliation bill to provide greater tax cuts. They need to cut social service programs to offset these tax cuts. And Medicaid is their target.

From our perspective, the 119th Congress should be *increasing* funding for Medicaid – not cutting it. The waiting lists continue to grow. There is a shortage of direct support professionals. Family caregivers are overburdened, and have no path toward ensuring their loved one's well-being when they are no longer able to care for them. School programs for special needs have been cut, at a time when they are most needed.

At this point, no one has any idea how this will turn out. The most likely scenario is that there would be drastic cuts to the share that the federal government will pay to the states (FMAP). This could be meted out in block grants to the states. There could be per capita caps, which limit the amount of money an individual might receive in a year, or over the course of their lifetime. And while members of congress are trying to find ways to justify making these cuts, it will be the state governors who will be forced to make cruel decisions about who gets completely cut out of services, and how much to cut from those who remain covered. Most governors are already having a tough time trying to balance their budgets without congress cutting their greatest source of funding.

We know, too, that the ripple effects of cutting Medicaid will cut into other services that will affect us all. The DSP shortage will only get worse, as providers will be unable to increase pay and caregivers will choose other jobs. Private providers will have to close some of their ICFs, nursing facilities, group homes, or day programs. People cut out of HCBS services will wind up going to hospitals for treatment. Hospitals will consequently become overcrowded, and will be forced to choose between turning away patients or facing bankruptcy. Those who lose their long-term services and supports will be at risk of living on the streets, or may end up in the county jail or the state prison system.

So, for the sake of our families and our loved ones, we have to tell the members of the 119th Congress to make:
"No Cuts To Medicaid".

In the meantime, we are still in the process of determining what other issues we can bring to the table. The issues we decide to focus on will depend on timing as much as anything, as Congress is currently focused on its own problems, not ours.

We need to remind Congress about the DSP shortage, but just like improving Medicaid and shortening the waiting lists, the solution to this problem requires more funding, not less. We are also concerned about the cutting back on research for autism and the rare diseases that may cause autism or developmental disorders. We still trying to improve supports for people who are dually diagnosed with ID/A and severe mental illnesses (SMI), who cannot find treatment due to the siloing of services and the lack of professionals trained to handle these coexisting conditions.

The new administration may present some opportunities. Republicans in Congress are more likely to support sheltered workshops and 14(c) programs than the Democrats have been. They might, or might not, be interested in changing the Settings Rule that has obstructed innovations in housing since the inception of the ACL, though they are unlikely to support increasing any funding for housing for people with I/DD and autism. And now that the ACL has been folded into the larger HHS system, there might be a way to change the policies that have governed the way Protection and Advocacy agencies (P&A's) use their funds. Our hope is that they will focus on protecting all people with I/DD and autism from abuse and neglect in all settings, and stop advocating for one-size-fits-all solutions.

But some matters may be better left off the table until the dust settles on the Medicaid issue and the new administrators of HHS and CMS make a clearer picture of their policies and priorities. We are grateful to Gayle and Cyndy and the folks at Health Policy Source for their guidance in this. And we are grateful to our members for sharing their stories with us and with decision-makers and elected officials. Our personal stories make all the difference.

So far this year, we have:

- Written 52 letters to the governors of every state and two U.S. territories to share our concerns about how cuts to Medicaid will affect their states, their budgets, their hospital systems, and their infrastructure, and how all of these will affect people with I/DD and autism, people with other disabilities, and non-disabled individuals. We have also emailed our concerns to the National Governors Association, the Republican Governors Association, and the Democratic Governors Association.
- Sent over 50 emails to every State Administrator of Developmental Services to encourage them to speak to their governors and their members of Congress to oppose cuts to Medicaid.
- Emailed every committee staffer on the Senate Finance Committee and Senate HELP Committee and to the Members of the House Energy and Commerce Committee to express our opposition to any and all cuts to Medicaid.
- Helped members to reach out to their federal and state legislators on the issues most important to their families and loved ones.
- Initiated new campaigns to speak for those with dual diagnoses of autism and severe mental illnesses and for organizations representing rare diseases with manifestations that may include autism.
- Tracked every bill entered in the House and Senate to find those that affect our loved ones with I/DD and autism.
- Continued to work with our friends at the National Council on Severe Autism, Together for Choice, and the Coalitions for the Preservation of Employment Choice on policy issues that concern people with ID/A to try to find common ground and support for our families and our loved ones.

VOR's Annual Membership Meeting

The VOR Board of Directors would like to invite everyone to our Annual Members' Meeting,
on Zoom, on June 8th at 3:00 pm

- Open meeting of the VOR Board of Directors
- Special Guests
- Reports from the States
- Our Annual VOICE Award

Details will be announced soon. Check our website for information. @ https://swww.vor.net

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

Thank you for your dues and contributions!

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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.

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

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The VOR Voice – Spring, 2025

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

VOR's 2025 Legislative Initiative

Washington D.C. *May 12 – 14, 2025*

Join us on Capitol Hill, as we meet with members and staff of the 119th Congress and key cabinet agencies to discuss issues that affect people with severe / profound I/DD, autism and severe mental illnesses.

This year is critical. Congress is trying to cut Medicaid.
Our families are at risk.

To register, please
Please click here
You must be a member of VOR to participate in this event

Unable to join us in D.C. this year?
You can still help by becoming a sponsor!

Diamond - $ 5,000
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Any and all gifts are welcome

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Please write "Leg. Init. 2025" on the check memo to specify that this is a contribution to the Initiative.