



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



It's hard to believe that another year has passed. So much has happened, so much has changed, and so much is about to change again. And yet, one thing has not, and will not change: the need for high quality care for people with severe and profound intellectual and developmental disabilities and autism (ID/A).

We would like to thank those who have come before us for setting the table here. If not for the foresight and vision of the founders of this organization, we don't know what would have become of our loved ones, Rosemary and Tom respectively. They understood that the best way to protect their loved ones with I/DD was to join with others who faced the same challenges, then to advocate and educate those who have the power to help us. Our work, their work, is never finished. And while we continue to work on the challenges we have faced in the past, we know that there will always be new challenges that lie ahead.

This year will see a new presidential administration and a new congress, both intent on making cuts to Medicaid. We don't know what form those cuts will take, but we can expect that they won't be designed to improve outcomes for people with severe or profound I/DD and autism. The most likely scenarios involve cuts or caps to the federal share of Medicaid payments, or FMAP, which will increase the burden on state budgets, forcing governors and state legislators to make the decisions as to which programs will be cut, and which people will no longer receive services through Medicaid. The shortage of direct support professionals (DSPs), and the low wages they receive, will probably be addressed by states, even though their wages are tied to the federal minimum wage.

However, there may be some opportunities open to us. We might be able to alter or eliminate the settings rule, which has stifled the creation of new models of residential care. There's a good chance that 14 (c) programs won't be eliminated by federal law, though states continue to try to phase them out. And there may be an opportunity to rebalance the way funds are allocated, changing the decades-long policies of favoring those who are most easily integrated into community settings while marginalizing the need for services for people with more severe intellectual, medical, and behavioral challenges.

To meet these challenges, and to take advantage of whatever opportunities may arise, we need your support.

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

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

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

We wish you all the happiest of holidays,

Joanne and Hugo

Joanne St. Amand - President
President, VOR Board of Directors

Hugo Dwyer
Executive Director of VOR – A Voice of Reason

One Family's Experience: Autism and Mental Illness By Mary Hurley

I write the following riff on severe autism and mental illness from the perspective of the mother of a 31-year young man diagnosed with autism at 3 years old and with mental health issues appearing in his teen years. No one said my son had a separate diagnosis of mental illness nor did they tell us the impact it would have on his life or that of his family. No one discussed accessing services from the Division of Mental Health at the time. All discussions throughout the years focused on his **Autism** diagnosis and his behaviors were thought to be a result of that diagnosis. This was a mistake, a mistake that continues to this day due to the way our services for those dually diagnosed are siloed within separate state agencies. Our family coped throughout the years by often isolating at home due to our son's behaviors and outbursts in the community; so, we were well accustomed to isolating at home long before Covid curtailed all social interactions for everyone.

I think, some history is helpful here: Our son's mental crisis could happen anywhere, at any time, and we realized we needed to be prepared with an exit strategy: How do I get him out of harm's way before he hits another person in the community, before the police are called or worse. And if you do need to call 911 and go to your local hospital emergency room, what can you expect. This did happen to us, and he was hospitalized for six days. After a day in the emergency room, where he was chemically restrained, my son was transferred to a regular floor. Why? He couldn't be admitted to the hospital psychiatric floor or seen by the hospital psychiatrist because of his developmental disability. The result was six days of trying to keep my son away from hurting staff and staff not knowing how to stabilize him.

Further, my options were to connect with CARES—Trinitas' Crisis, Assessment, Response, and Enhanced Services team and have him transferred to Trinitas, a specialized unit for individuals living with mental illness and a developmental disability. This would be a short-term stay. However, a bed at Trinitas, at the time, was not available. So rather than keep him in the hospital until a bed was available, I brought him home. I was also very aware of how further trauma could affect him, as I had been advised by his psychiatrist at the NYU Child Study Center to do all that I could to not cause him trauma. Being in a psychiatric unit for any amount of time was certain to do that.

Additionally, I just finished reading: [The Body Keeps the Score](#), by Bessel van der Kolk and the text resonated with me, in that, his description of what happens to the nervous system when reliving past trauma mirrored the episodes that I had seen my son go through. I also remembered that trauma can be an accumulation of small "t" trauma: bullying in school, etc. that happens over the years resulting in PTSD. So, interventions for this are different.

With that said, I connected with YAI, an organization that was creating a few stabilization homes in NJ. I ended up using some of their protocols in my home to create a therapeutic environment for my son. To deal with his aggression, I became trained in the [Ukeru](#) method. This method entails a new way of managing crisis.

It teaches a variety of physical techniques that minimize the need for physical restraint. It involves a system of blocking techniques with the use of pads that protect both the aggressor and the person receiving the aggression during behavioral episodes. I needed to go through an online and in-person training to become certified. Bottom line: this method should be used more widely and has helped me immensely to stabilize the situation in my home.

Another model that is coming to the southern part of New Jersey and is in some 14 other states is the START Model: Systemic, Therapeutic, Assessment, Resources, and Treatment – provides community-based crisis prevention and intervention services for individuals with intellectual and developmental disabilities and mental health needs. This program will help to reduce emergency room visits, hospital admissions, and the need to call law enforcement at the outset of a behavioral crisis which, in of itself, causes trauma as I mentioned above.

Follow the NADD - an association for people with intellectual and developmental disabilities and co-occurring mental health conditions. This association sponsors the The DM-ID-2 & Accompaniments. This publication comprises 100 experts from around the world that get together to update the DM-ID to accompany the DSM-5. The current edition, DM-ID-2 is to facilitate an accurate diagnosis for individuals with developmental disability and co-occurring mental illness. The NADD also sponsors certification programs, etc. Check out their website: <https://thenadd.org>



(One Family's Experience, by Mary Hurley - continued from the previous page)

Follow the Link Center - funded by the Administration for Community Living (ACL) and its mission is to improve supports for children and adults with developmental disabilities, brain injuries, etc. with co-occurring mental health conditions to assist state agencies in policy, service design and sharing resources with individuals, families, DSPs and clinicians. They host Zoom meetings throughout the year which give families opportunities to give input into their circumstances. Sometimes, the lived experience of families with individuals with profound needs is not reflected in the discussions. Check out their website: <https://www.nasddds.org/the-link-center/>

Follow the National Alliance on Mental Illness (NAMI) - an alliance of more than 600 State organizations and local affiliates that work to educate, support, and advocate to improve the lives of people with mental illness and their loved ones. <http://www.nami.org>

I hope that these various initiatives and select resources have an impact in making my son's life and those of others like him better. To better experience the joy in life and to decrease the mental anguish that sometimes happens is my wish for our loved ones with a developmental disability and co-occurring mental illness.

Action Alert – Please Take Two Minutes to Support 14(c) Programs for People with Intellectual Disabilities and Autism

The Department of Labor's Wage & Hour Division of the Department of Labor, which oversees employment programs for people with intellectual disabilities and autism (ID/A), has issued a proposed rule in the Federal Register that would phase out the use of Commensurate Wages under Section 14(c) of the Fair Labor Standards Act. This new rule would virtually eliminate the only option for tens of thousands of people with moderate to severe levels of intellectual disability, autism, and behavioral disorders. There is no proposal to create programs to replace these opportunities, only the false assumption that facility-based employment services will somehow adapt to the new standards.

There is no need to phase out these opportunities. Over 90% of the people who work in 14(c) programs have intellectual disabilities, and they are practically unanimous in their support of protecting these opportunities. It is not uncommon for people working in facility-based employment to also work in competitive employment. The two types of employment are not mutually exclusive, and we can continue to support both programs as we have for the past 86 years.

This is a matter of ensuring that individuals and their families have the right to make their own choices, and that those choices should be respected by the government agencies that oversee their well-being and by others in the disability community, especially by those that demand that *their* choices be respected.

The value of 14(c) programs is not measured by wages alone. The programs provide **meaningful daily activities** for people who have skills they would like to use and develop, but are difficult to place in integrated work environments, even by companies that are trying to provide employment for people with ID/A. They give people with ID/A the option of working among their peers, in a safe and supervised environment.

There is a comment period from now until January 17th, and we ask our members to send comments to the Wage & Hour Division to express your opposition to this rule and your support of 14(c) provisions for people with intellectual disabilities and autism.

Please go to the Wage & Hour's Comments Page and submit a short but impassioned comment about what these programs mean to you, your loved ones, families you know, or the ID/A community as a whole.

It only takes about two minutes of your time to participate. We ask that all of our friends and families take part! Please note that all paper mail to federal agencies like DOL has to be screened through a mailing service that can take about a month. To make sure your submission is received in time to be counted, please use the Wage and Hour Division's website, below.

To read the announcement on the proposed rule and submit your comments, please go to:

<https://www.federalregister.gov/documents/2024/12/04/2024-27880/employment-of-workers-with-disabilities-under-section-14c-of-the-fair-labor-standards-act>.

Why Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID) should remain open and why an ICF is the best option for my sister, Rosemary... By Joanne St. Amand

First and foremost, I believe families and guardians should have a “real” choice of residential options for their family members with Developmental Disabilities/ Intellectual Disabilities/Autism (DD/ID/A). And, to have a “real” choice, there needs to be “real” options, not just a group home or a nursing home! Second, everyone with ID/DD/A does not require the level of care in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID) to survive or thrive.



Rosemary and me

Rosemary will be 70 years old in a few months. She is the youngest of three. Our older brother, Anthony and I are her co-guardians. Rosemary was born profoundly intellectually disabled, a complete surprise to my parents because nothing was unusual about her birth. Typical of the doctors at that time, they advised my parents not to take Rosemary home from the hospital. My parents ignored their advice, and my mother went to the hospital every day for the next 3 months until Rosemary could feed from a bottle. As soon as she could, the feeding tube was removed, and Rosemary came home.

Rosemary needs help with every aspect of her life. My parents lifted and carried her everywhere. My mother pureed her meals with our kitchen blender and one of us would feed her. Rosemary lived with our family until she was 20. Then, my mother began having health issues. So, our parents made the difficult decision to look for a placement for Rosemary. They wanted to find her a home that provided the care and services she needed while they were still young enough to be active in her life, watch over her in her home, make changes if needed, and not leave such responsibility to Anthony and me.

My parents explored all the options and made an informed personal choice to place Rosemary on the waitlist for admission to a NJ state-operated developmental center, a federally licensed ICF/IID) She was admitted within the year.

An informed, personal choice in residential settings...

Our family’s choice for my sister, an ICF/IID, is the most comprehensive program offered by the Centers for Medicare and Medicaid Services (CMS). At the heart of this program is something called an “Active Treatment Plan.” Only federally licensed ICF/IID programs offer this. Any facility, whether it is a large state-run center, a smaller privately run facility, or even a 4-bed group home, can acquire this licensing from CMS, if they meet the “Conditions of Participation” required by CMS. It is the ICF “program with services” that is crucial, not the bricks and mortar of the buildings where the services are provided. Why am I stressing these points? Because we are being led by ideologists, protection & advocacy agencies, disability advocates, and people with vested financial interests in the *business* of developmental disabilities that everyone does better “in the community.” This is not true. Closing ICF/IIDs would be the biggest cut-back in someone’s medical coverage and services imaginable for an individual who cannot live without them. Rosemary is someone who requires the level of services provided in an ICF/IID licensed program to live a good quality of life.



Rosemary with my brother Anthony

The SOS of options

No one is prepared for this journey. No one chooses to move their child out of their home without tears and heartache, even when they know it is the best option for all concerned.

When I think of an ICF for Rosemary, I think **SOS... Services, Oversight, and Socialization.**

Services are what keep Rosemary healthy and thriving. She is surrounded by trained direct care staff with many, many years of experience, two on-site doctors experienced in treating individuals with IDD and autism and a plethora of medical conditions, nurses on every shift, speech and occupational therapists, a nutritionist, dental hygienist. Although Rosemary is nonverbal, her speech therapist plays a critical role in her well-being by monitoring her dysphagia and determining the appropriate moisture level and texture of her pureed food. Together with her nutritionist and medical team, Rosemary’s weight has been maintained and the risk of aspiration minimized. And they established a backup plan for the days she does not want to eat so she continues to get enough fluids and calories. This is so important because as soon as Rosemary is not feeling well, she does not want to drink, often gets dehydrated, Her sodium levels spike and protocol sends her to the hospital for hydration. *(continued on following page)*

Her three ER visits this year were traumatic for her. Her veins are small, so it takes multiple attempts to put in an IV line, and often she ends up with a PICC or midline catheter. Nothing is straightforward for Ro, or for thousands like her.

Oversight is important, and especially so because Rosemary cannot communicate. She cannot tell you if she is sick or in pain, hot or cold or if something is wrong. Her ICF/IID must abide by the CMS State Operations Manual for ICF/IID, Appendix J, a 247-page document which contains guidelines for everything from the minimum and maximum temperature of her food or bedroom, to staffing requirements, to the members of her Interdisciplinary Team (IDT) who develop her personalized “Active Treatment” plan. The IDT thoroughly evaluates Rosemary’s abilities and sets goals. They recommend a program to assure her well-being and promote improvement in her abilities. One such recommendation is that a staff member must have “eyes on Rosemary” at least once every 15 minutes. For Rosemary who needs help with every aspect of daily living, one goal is to be able reach for and hold an object like a fork, so one day she may be able to feed herself, or for her to make some decisions like a nod if she wants to wear a certain outfit that day. Rosemary’s IDT consists of a staff member from each area (medical doctor, dental hygienist, direct care, nutrition, recreation, PT, OT, psychology, social worker, etc.) usually between 10-15 people who sit in a room with me and Anthony (we are her co-guardians), at least once a year. Unique to an ICF/IID is the “Active Treatment” plan. No other program or facility offers an Active Treatment plan like that required of an ICF/IID. They may say they do, but they do not. The Active Treatment plan is comprehensive and is what requires the ICF to provide sufficient, needed interventions and services, such as doctors, nurses, therapists, etc. on-site as well as much, much more.



Anthony and Ro

Our parents chose the ICF/IID for Rosemary’s new home because it is the only place where the government mandates this level of care. Rosemary and the others who are profoundly or severely intellectually disabled and require this level of care make up only about 5% of the entire population with ID/DD/A. The overwhelming majority are diagnosed with mild or moderate ID/DD/A. However, it is still imperative that we preserve the ICF/IID program so it is available, and those individuals and families can choose it for their family members who require this level of care.

Socialization is a less tangible but important aspect of Rosemary’s wellbeing. Once, while walking the grounds of Ro’s ICF with a NJ legislator, I was asked if the services Rosemary required were present in the “community” would my family have chosen a group home over her ICF. I told her I did not think so. First, the level of staffing, on-site doctors and 24-hour nursing at Rosemary’s

ICF could never be matched in the “community”. Also, Rosemary is with her peers. These are her friends, just like students in a dorm at a college or senior citizens in a gated community. People like to be with people like themselves. Why not this population too? When I visit Rosemary, she looks for her friends. Her eyes follow the other residents as they stroll or roll down the hall. Rosemary’s focus moves away from me when she sees her friends go by.

As part of the Active Treatment plan the ICF must have professional program staff trained in recreation. Ro’s center has an entire recreation department. At her recent IHP meeting, her recreator informed the IDT that Rosemary participated in numerous activities during the year both in-house and in the “community.” Birthdays, holiday parties, dances, cookouts, Family Day, and textile activities are celebrated. Rosemary went to the mall, the movies, a petting zoo, and local attractions like “Northland.” Her social life is very full!



My husband Bob and me with Rosemary

Rosemary's ICF/IID successfully addresses every part of her life and has done so for almost 50 years. We are grateful for VOR and all its members past and present, for their many years supporting and protecting those with DD/ID/A and having real choice in residential settings. My brother Anthony and I are proud that our parents made the right choice for Rosemary, and we will be forever at her side.

We want to hear from you!

- Do you have a personal story to share in the VOR VOICE?
- Is there a new law or DD action happening in your state?
- Do you have a newspaper article for our Friday News Update?

Write to us at info@vor.net and let us know how we can help.

Dispelling the Myth of Institutional Bias

There is no Medicaid “Institutional Bias” for Persons with Intellectual and Developmental Disabilities (I/DD)

The allegation of a Medicaid institutional bias for people with I/DD needing Long-Term Services and Supports (LTSS) is simply not true. It is based on two false premises: (1) that all institutional services are mandatory and all home and community-based services (HCBS) are optional, and (2) that more dollars are spent on institutional services than on HCBS services.

First, all Medicaid programs for people with I/DD are optional – whether provided through Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID) or the HCBS program. **Second**, as detailed below, far more Medicaid dollars are spent on HCBS than on ICFs/IID services for people with I/DD.

How, then, did this myth come into being? The answer is by mixing the funding sources for very different populations, (1) the elderly and physically disabled who are served through the nursing facilities (NF) program, a mandatory Medicaid program, and (2) people with I/DD, who receive funding through optional ICF/IID and HCBS programs. By combining the dollars spent on the NF and ICF/IID programs as “institutional” funds, proponents of community funding represent that there is an institutional bias.

When only programs for people with I/DD are separated out, it is absolutely clear that there is neither a bias in the nature of the program nor in the amounts spent for institutions. (Source: [Medicaid Long Term Services and Supports Annual Expenditures Report Federal Fiscal Year 2019 December 9, 2021](#))¹

A) ICFs/IID comprise 12% of total Medicaid “institutional” spending; nursing facilities account for 80% of total Medicaid “institutional” spending. The remaining 8% is allocated to other institutional expenses, including Mental Health Facilities, Disproportionate Share Hospitals, and other institutional long-term services and supports. ([See p. 29](#))

B) Less than 5% of total Medicaid long-term care expenditures are for persons with I/DD served in ICFs/IID, while 59% is spent for community-based long-term care services for people with I/DD. ([See p. 83](#))

Figure A. Total (state + federal) Medicaid Institutional Long-Term Care Expenditures: \$61,243,655,747

ICF/IID:	\$ 7,873,488,377
Other Institutional:	\$ 5,493,166,282
Nursing Facilities:	\$ 53,370,167,370

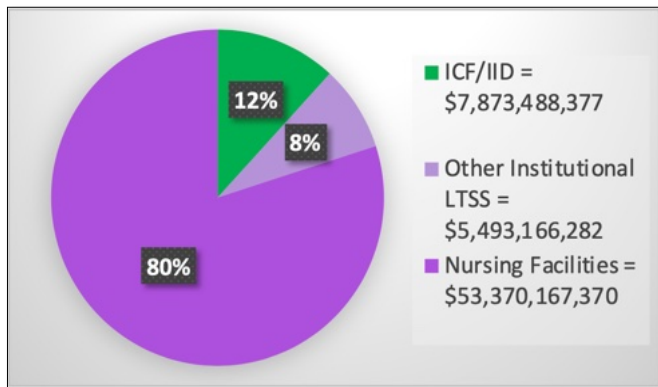
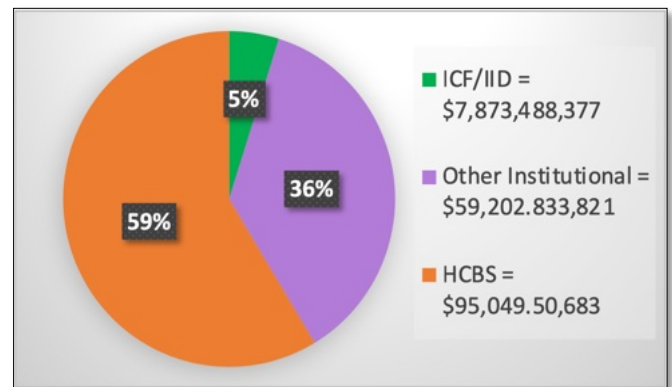


Figure B. Total (state + federal) Medicaid Long Term Care Expenditures: \$162,125,902,881

ICF/IID:	\$ 7,873,488,377
Other Institutional:	\$ 59,202,833,821
HCBS:	\$ 95,049,580,683



The decades long trend for total Medicaid LTSS expenditures from 1988 -2019 has been a large increase for HCBS expenditures from 12% to 59% and a substantial decrease in institutional expenditures from 88% to 41%. (Graph pg. 14) As previously stated, less than 5% of total Medicaid long term care expenditures are for persons with I/DD served in ICFs/IID.

The ICF/IID program is not the cause of rising Medicaid costs. It is a tiny and falling percentage of all Medicaid funding and a good investment for both the federal government and the states to care for some of their most needy citizens.

¹ All sources: Medicaid Long Term Services and Supports Annual Expenditures Report Federal Fiscal Year 2019 December 9, 2021 <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures2019.pdf>

(Continued from previous page)

Why, and how, does this myth persist? The myth of an “institutional bias” persists because it supports the “one-size-fits-all” narratives of those who insist on applying simplistic solutions to complex problems. These policies are most often voiced by self-advocates and families of people who thrive in inclusive environments, and have been accepted by federal and state legislators and the respective agencies that oversee disability policy.

But what’s most disturbing is the deliberate misuse / abuse of the term “institution”. Schools, churches, our government - and yes, even marriages – are all institutions. And different people have different opinions about those institutions, based on their own experiences. But as applied to long-term care options for people with intellectual disabilities and autism (ID/A), “institution” has been re-framed as a dirty word, and promoted as such by people who have no real experience with ICFs or with people with severe/profound ID/A who rely on that level of care.

Contrary to this view of, there are some institutions, such as ICFs and Skilled Nursing Facilities (SNFs), that are essential to the well-being of people with severe / profound ID/A, especially those with complex medical conditions. These institutions provide appropriate services in a least restrictive, most integrated living environment depending on individual need. There are other institutions that are used to house people with ID/A that are not appropriate to their needs but that are frequently used to fill the void in our safety net. These include hospital emergency rooms, psychiatric hospitals and wards, forensic facilities for those with ID/A who commit aggressive, violent, or criminal acts, and ultimately, the prison system for those who cannot be accommodated elsewhere. These institutions do not provide any of the appropriate therapeutic services for people with ID/A, possibly putting them in harm’s way.

Those who receive services through the HCBS branch of Medicaid often express a perceived threat of being “forced into an institution” if their services are reduced or cut off in any way. This can, and does happen, though not as implied. Very few people move from HCBS to an ICF, and then only with great effort and clear evidence that this is the most appropriate placement. The most common instances occur when people living in group homes have an extended hospital stay and find out upon discharge that their placement in that home is no longer available – the HCBS system does allow providers to turn an unoccupied bed over to another individual after as little as three weeks. Individuals who develop dementia or new medical conditions as they may be moved out of their group homes if the facility can no longer provide the type of care appropriate to their new stage of life. Persons with aggressive behaviors may be forced out of their group homes in order to protect staff and the other residents. Indeed, Special Education students with autism who have aggressive behaviors and have a violent outburst at school are often referred to law enforcement officials, and may even be arrested and charged with the consequences of behaviors they cannot control. Those living in their family homes may find it too hard to find outside caregivers, or their parents age and can no longer provide appropriate care for them.

In many of the above situations, clients who had been receiving long-term services and supports through HCBS and can no longer be accommodated within the HCBS system *do* wind up in inappropriate institutional settings mentioned previously. And we would be the first to agree that this isn’t right. But this is a failing of the greater DD system, and the HCBS system in particular. This is not the fault of the ICF system.

So why the confusion? Again, this is often a deliberate part of the narrative of those who support “one-size-fits-all” solutions. They picture ICFs as the old crowded warehousing hospitals and institutions of the past.

Modern ICFs: The truth is that modern ICFs have been greatly improved through the advocacy of families needing this level of care.

An array of services must always be available to meet the high level of needs of people with ID/A. ICFs provide 24/7 access to doctors and nurses, and often include on-site dental services, physical therapy, behavioral therapy, occupational therapy, music therapy, water therapy in swimming pools, daily programming and activities, as well as furnishing disability-appropriate transportation to doctors, shopping, restaurants, and community events. Dedicated staff provide basic daily need of many individuals who need maximum assistance with bathing, toileting, eating, and helping to get them to therapies and programming.

Families currently using ICF services are working to keep this level of care as an integral part of a full continuum of care for people with ID/A.

Monthly Donations to VOR

Many of our families prefer to make monthly or quarterly gifts to VOR, rather than making one large donation at the end of the year. They say this is easier to budget, and if and when the spirit moves them, they can always make an extra donation.

If you would like more information about monthly giving, please contact info@vor.net or go to:

<https://interland3.donorperfect.net/weblink/weblink.aspx?name=E140301&id=5>

Action Alert – Please Help Pass Legislation Recognizing Direct Support Professionals

For several years, we have been working with members of Congress, the National Association of Direct Support Professionals, the Senate Committee on Aging, Labor Unions, and a coalition of advocacy groups including National Council on Severe Autism, Together for Choice, ANCOR, The Arc, Caring Across Generations, and others to promote the recognition of Direct Support Professionals as a class of Health Care Workers and to improve their wages and benefits, training and accreditation, and paths to long-term careers in health services.

One key component to this effort has been the “Recognizing the Role of Direct Support Professionals Act” (HR.2941/S.1332). This bill has already passed the Senate and has moved through committee in the House. It still needs to pass the House before it can go to the President’s desk to be signed into law. With time running out before the end of the 118th Congress, we ask for your help to get this bill passed into law.

Our friends at the Profound Autism Alliance have set up a link to send comments to the House to encourage them to pass the bill. We ask you to join them in supporting this bill by signing on and submitting your own comments.

Please go to <https://www.votervoice.net/BroadcastLinks/rGmWpSfw29zJ3xXGpBtnYw> to add your voice.

Planned Giving To VOR

Several of our members have shown interest in making charitable contributions to VOR. Here is a short overview of some of the most popular forms of planned giving.

As always, we recommend that you **contact your tax professional or account administrators** to determine which type of contribution is right for you, and to ensure that your donation follows the protocols established by the IRS and the organizations that administer your financial assets.

Make a Charitable Distribution from your IRA

You can make a qualified charitable distribution (QCD) from your IRA and make an immediate impact.

- You must be age 72 or older.
- Your gift must be transferred directly from your IRA account to VOR.
- Your gift is a transfer of funds from your IRA to VOR, so while you do not receive a charitable deduction, it does not create taxable income for you.
- You may transfer up to a total of \$100,000 per year (individual) or \$200,000 (for a married couple).
- If you are required to take a Required Minimum Distribution (RMD) from your IRA, your gift can count towards it, but your gift is not limited to your RMD. If you are using a checkbook issued by your IRA administrator to make your gift, please send your gift as early as possible to ensure that it qualifies for a distribution in the current year.

Add VOR as one of the Beneficiaries of your Retirement Plan

Naming VOR as a beneficiary of your retirement account can be an attractive option for creating your enduring legacy and reducing income and possibly estate taxes for your loved ones. Because retirement plans are taxed differently than most assets, they may become a tax liability.

Make A Gift of Securities

You may contribute stocks, bonds, and mutual funds that have grown in value. Potential benefits include:

- You may receive a charitable income tax deduction for the full market value of the securities
- You could avoid paying the capital gains tax on any increase in the value of the stock you give.

Make a Legacy Contribution through your Life Insurance Policy

If you have a life insurance policy that has outlasted its original purpose, you can use it (or a percentage of it) to reduce your taxes while helping people with I/DD and their families.

For more information, please contact Hugo Dwyer at hdwyervor@gmail.com or info@vor.net
or go to <https://www.vor.net/get-involved/donate-to-vor/item/membership-donations>

Acknowledging Louisiana's Lieutenant Governor Billy Nungesser's Visit to Pinecrest and the Importance of State-Operated Intermediate Care Facilities (ICFs) By Casey Henry



We, the families of the Pinecrest community, want to extend our deepest thanks to Lieutenant Governor Billy Nungesser for recently visiting Pinecrest, a state ICF, where he was able to witness firsthand the invaluable role Intermediate Care Facilities play for individuals with severe and complex disabilities. For many of us, Pinecrest is more than just a facility. It's a lifeline for our loved ones who need comprehensive, round the clock care that addresses both their medical and developmental needs. Lieutenant Governor Nungesser's visit helped shed light on the significance of places like Pinecrest that serve and have served as homes for those with profound needs for over 100 years.

During his visit, Mr. Nungesser was struck by the scope and dedication of the services provided. Pinecrest stands as an example of a facility designed to provide not only medical support but also a holistic community environment. From the on-campus school to the numerous recreational and therapeutic activities, every aspect of Pinecrest is tailored to ensure residents receive enriched care. With facilities like barns for therapeutic animal interactions and spaces designed to foster both physical and mental well-being, Pinecrest exemplifies the level of care that individuals with severe disabilities truly deserve.



VOR's Terry Lafleur and Casey Henry with State Rep. Rhonda Butler and Lt. Governor Billy Nungesser

Many of our loved ones cannot travel to our nation's capital or attend local legislative hearings they rely on us, their family members, to advocate on their behalf. For this reason, we encourage other VOR members to invite their state governors, legislators, and representatives to visit their local ICFs. Direct engagement is essential in fostering awareness and appreciation for

the critical role these facilities play. Mr. Nungesser's visit highlighted an important reality there are leaders who may not yet be aware of the specialized resources and comprehensive care ICFs provide. By welcoming more legislators to these facilities, we can cultivate a greater understanding of the needs of those who cannot advocate for themselves.



"And all of the food for this event was prepared by the residents of Pinecrest!"

ICFs like Pinecrest are essential for individuals with severe medical and developmental disabilities, and the dedicated staff from nurses and therapists to administrators work tirelessly to ensure the health, safety, and happiness of each resident. Our hope is to spread the word and inspire increased support for these facilities, which provide peace of mind to countless families like ours.

Lieutenant Governor Nungesser's support is a step forward, but we need to continue inviting and educating our leaders so they understand the vital role that ICFs play. Our loved ones deserve nothing less than the compassionate, specialized care that facilities like Pinecrest deliver. Let us continue to open our doors and our hearts to those who can make a difference, creating a future where every individual's unique needs are valued and met.

Pinecrest Prepares for the Holidays – Pictures from Terry Lafleur



PINECREST ❤️ VOR!



VOR ❤️ PINECREST!

Separating Policy From Politics

VOR is a 501(c)(3) organization. As such, we have to keep politics at arms' length. We have members who are committed to each political party. When we go to D.C. or reach out to federal, state, and local officials, we do so with no regard to their party affiliation. Our mission is to help families of individuals with I/DD and autism (ID/A) and to protect their power to make informed choices from a wide range of residential options and employment options.

But there's a difference between politics and policy, and this is where we have to tread carefully. There are policies that help people with ID/A, there are policies that only help some people with ID/A and not others, and there are policies that just make things more difficult for all people with ID/A. It's important that we inform our families about these policies, and that we advocate - bringing a voice of reason to decision makers, most of whom know little or nothing about our loved ones' many challenges.

Neither political party places a high priority on promoting better options for people with severe and profound I/DD and autism. But within each party, there are a few elected officials and staffers who understand, even empathize with our loved ones' need for services. And these are the people who give us hope.

Looking Back: The Biden Administration and the 117th and 118th Congresses

In general, the policies of the last four years have continued, even accelerated, the direction the last twenty-five years of disability policy, which have favored integration and community placements, empowering self-advocates, and marginalizing the families of people with severe and profound ID/A.

The Biden Administration had big plans when it took office. Biden had inherited the Covid pandemic from the first Trump presidency, and put measures in place to halt its spread. Then, they sought to reimburse the American public for revenues lost during the shutdown with the American Rescue Plan Act, which appropriate huge sums of money for states, small and large businesses, schools, and among other groups, people with disabilities. Unfortunately for our folks with severe and profound ID/A, only people and providers of Home- and Community-Based Services (HCBS) were included in these appropriations.

President Biden also sought to work with Congress to make the Better Care, Better Jobs Act, which included appropriations of \$400 Billion for HCBS only. VOR and other groups advocated for parity funding for people in non-HCBS long-term supports and services through Medicaid. We were told by the people who entered these bills in the House and Senate that we needed to find a member of congress to introduce *our own* bill for this, which was both a highly unlikely proposition and a fairly snide way of saying no. the \$400 B was later reduced to \$350 B, then \$150 B, but the bill never passed. House and Senate Democrats subsequently introduced other bills for HCBS-only appropriations in the 117th and 118th Congresses, but none of these bills passed either.

Despite missing these HCBS-only opportunities, the Biden Admin, the two concurrent congresses, and, most notably, the Administration for Community Living (ACL) continued to push policies that supported community integration and empowered the self-advocate community, giving them a disproportionate voice in directing policy for all people with ID/A, no matter the severity or the circumstances of the individual and their family. While VOR argued for individuals and their family's right to choice, the self-advocates continued to campaign that only *their* choices were right for people with ID/A. This effort became most apparent in the recent meeting of the President's Committee for People with Intellectual Disabilities (PCPID), where the majority of members were self-advocates, and insisted on taking half of the time of the meeting to air their personal grievances with DD services, taking away time that had been allocated to representatives of various DD service agencies discussing new programs intended for *all* people with ID/A. The voices of families that held different views were stifled. We were not given representation at these events. The PCPID did not represent all people with ID/A, only a vocal minority.

The same perspective dominated policies about employment of people with ID/A. The Transformation to Competitive Employment Act was written not only to promote increasing funding for the kind of competitive, integrated employment that those with milder ID/A favor, but would eliminate compensatory wages and phase out 14(c) programs offer opportunities to people with more severe ID/A, who are unlikely to be accommodated by businesses offering competitive wages. In the waning weeks of his administration, President Biden has announced that he wants the Department of Labor to end these programs, with no regard to the fact that they only serve a small cohort of ID/A individuals, and that those individuals have almost unanimously supported maintaining these programs and providing more such opportunities. Sadly, Mr. Biden appears to have forgotten the words of his father, which he repeated often

during his campaign in 2020, that, “A job is about a lot more than a paycheck. It’s about your dignity. It’s about respect. It’s about *your* place in *your* community.”

Looking Ahead: The Second Trump Administration and the 119th Congress

It’s too early to say what will actually happen with the second Trump administration and the Republican-dominated House and Senate, but proposals and recommendations from the Heritage Foundation’s Project 2025, the Republican Study Committee, and Trump’s own Agenda 47 campaign have all called for severe cuts to Medicaid services as a way to soften the blow to the national debt that will come from renewing tax cuts from the first Trump administration, which are due to expire soon.

It’s also too early to say what form those cuts will take and which people will be cut from services and which people will be spared. There has been talks of cuts to the federal government’s share of Medicaid payments to states, known as the Federal Medical Assistance Percentage (FMAP). If this happens, it will be up to the states to make cuts to their own programs. Or there could be lifetime caps on how much an individual can receive from Medicaid. There are any number of other proposals being discussed, but so far, no one has clearly proposed excluding those with severe or profound ID/A from any of these cuts.

It’s also unclear as to what role the new congress will take in supporting or opposing any of these proposals. Members of the 119th Congress may take a traditional view of having the legislative branch control the excesses of the executive branch, or they may see this as an opportunity to enact policies that had long been imagined, but never considered likely to pass. And it’s unclear as to which of President-elect Trump’s appointees will be approved by Congress, and how they are likely to oversee their new offices. It is clear, however, that neither Robert F. Kennedy, Jr. nor Dr. Mehmet Oz have any experience working in, much less managing, federal agencies of the magnitude of Health and Human Services (HHS) or the Center for Medicare and Medicaid Services (CMS).

Despite these challenges, there may be some opportunities for our families in the coming year:

- The Supreme Court’s ruling on the Chevron Deference case may provide an opportunity to eliminate the Settings Rule, which has stifled the creation of innovative housing solutions for people with severe ID/A.
- It is unlikely that the Trump Administration will support eliminating compensatory wages and 14(c) programs, and may even overturn any last-minute attempts to close them by the Biden Administration, its Department of Labor, or the 118th Congress.
- Federal agencies like the ACL may be under scrutiny by the new administration, and HHS may rebalance its focus away from supporting policies that favor those with mild ID/A and marginalize people with more severe challenges toward a more equitable recognition of people with all levels of intellectual disability.

What VOR is doing to prepare for the Second Trump Administration and the 119th Congress

We are in the process of preparing letters to the Transition Team and key players, including RFK, Jr. and Dr. Oz, letters introducing VOR to the entire membership of the 119th Congress, and submitting comments opposing the elimination of 14(c) to the outgoing Dept. of Labor before the end of the January 17th comment period. We will continue work with peer advocacy groups and unite with new groups to support our principles, and we will continue to advocate for better wages, training, recognition, and respect for the DSP workforce.

How can you help? Please join us on Zoom for our Networking Meeting on January 27th, 2025 and join us in person for our annual Legislative Initiative in Washington, D.C. for a few days in May.

Action Alert – How You Can Help

VOR Networking Meeting – January 27, 2025 – 4:00 pm Eastern time on ZOOM

Please join us to discuss the challenges and opportunities that we will tackle in the coming year. This event is open to VOR members only. To register for the Zoom meeting, please write to info@vor.net by January 24th. You will receive a confirmation email, followed by a link to the meeting one hour before it starts.

Join us in Washington this May for our Annual D.C. Legislative Fly-in.

Save the Dates: The tentative dates for this event will be to arrive and network on Monday, May 12 and attend meetings with congressional staff, committee staff, and representations of federal agencies on Tuesday, May 13 and Wednesday, May 14. Please stay tuned for details, which will be posted in the Weekly Newsletter and on our website.



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

**The VOR Voice – Winter, 2024
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- *Join us in Washington in May for our Annual Legislative Initiative – Page 11*

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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