



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



As you well 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 intellectual and developmental disabilities and autism (I/DD/A). You have been so graciously investing in VOR through your membership dues, donations and advocacy and share in the intangible benefits of supporting individuals through the very first national organization to

advocate for the right of all 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 supports not only choice in all residential options but other aspects of our individuals' lives including a full array of employment opportunities, as suited to their skills and their choice of settings in which to work and of course access to the most appropriate care and services needed for the highest quality of life.

As grateful as we are for your support, in this issue are articles written by our members who give you a glimpse into their life experiences and why they are grateful for the support of VOR. One member tells the story of her long search for a home for her brother after his provider closed his group home, and how other members of VOR led her to placement in a state-operated intermediate care facility. Another article is written by a direct support professional describing how he became immersed in helping his "unteachable" client learn how to read. In another article we talk about the wisdom of deceased member Jill Barker and the gift of her blog. Together we are stronger and smarter. And we need to be. Our family members with I/DD/A represent only about 5% of the entire spectrum of individuals with I/DD and autism. We are the minority of the minority and must work hard to be heard, and even harder to affect policy that will benefit our loved ones.

If we do not speak up for them, who will? We depend completely on the generosity of you, our members, and supporters to fund VOR so we can continue to do our work. Every one of you is important to our survival and every dollar really does count. We are thankful for all your years of support to VOR. If you have the means, we again must ask that as you plan your year-end charitable giving, you will please consider a gift to VOR.

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

One of the most important ways is to give of your time and talents, especially your website and multi-media skills. You can share your story with us, for the Voice. Most of all, we encourage you to share your story with your state legislators, tell them your concerns, and ask them to visit your loved one in their home to better understand their critical needs.

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

We wish you all the happiest holidays and a healthy new year ahead for you and your loved ones.

Joanne St. Amand  
President, VOR Board of Directors

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

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

## A Journey To Literacy By Tom Gilbert

In March of 1991, at Alpha 2 Northeast Care Center (an ICF/IID), at an Annual ISP (Individual Service Plan), a client at Alpha 2, Neil Burke, stated that he wanted to learn how to read. He'd been institutionalized since the age of six and had never attended school.

I was QMRP (now QIDP - Qualified Intellectual Disabilities Professional) at the time and in charge of the ISP meeting. I was also a student in the master's program in Special needs multi-handicapped at Cleveland State University (CSU). I had never heard any mention of literacy as being a possible intervention for folks with ID/DD.

Oddly enough, at the same time as the ISP meeting, the Medicaid surveyors were on site at our company for their annual survey. One of the surveyors was sitting in on Neil's meeting. She casually turned to me and said, "This is his wish; you will ensure that it happens. And, by the way, I will return in six weeks for my 'look behind survey' to see that it is happening."

So, I called every literacy organization I could find to see if I could get a literacy program started for Neil. I called every City, County, State, and Federal agency I could find, and received word from all of them that it could not be done, it was not possible, and to just forget it.

**'Rock and a hard place.'**

One of my colleagues, Carol Gress, Social Worker, suggested I call Project Learn, which is connected with Laubach Literacy International in downtown Cleveland. I asked them if they could assist, as they often help "normal" folks who had fallen through the educational cracks, and maybe they'd help Neil. I called and told them about Neil and they said sure. But before I hung up, I mentioned that he was diagnosed MR (term at the time). They literally screamed at me and said it could not be done, and that they weren't allowed to assist those with MR. I then pleaded with them that I'd called everyone else on the planet, and what if I could come down to their facility and take the two Saturday afternoon sessions to become an expert in literacy instruction and bring the materials back to the group home so I could work with Neil there?



**Reading with Christine**

Well, I did have library privileges at CSU; so, one Saturday I went to the library and the head librarian was there filling in for someone else. The place was empty. I explained who I was and what I was looking for, and she said, "Come here, I'll show you what we have." This was 1991. Recently, all of the 4<sup>th</sup> floor journal articles (millions upon millions of them), had been re-catalogued on the ERIC computer system. She typed in the term 'Mental Retardation' and it showed that there were approximately 125,000 articles on the 4<sup>th</sup> floor on MR. She then set it aside, and then she did a search for Literacy, and found another approximately 125,000 articles on literacy. Then she said, "watch this," and she cross-referenced them. There were just 6 articles, combining MR with literacy, and they were all on a thing called 'functional literacy': Teaching folks with MR survival words: 'Enter' and 'Exit' for buildings, 'Men' and 'Women' for bathrooms, 'Coke', 'Pepsi', 'McDonalds', 'Danger', 'Poison'; maybe 20 to 25 single words that might be useful. **Nothing** on actually teaching these folks how to read, ever, anywhere in the whole world at this time. And here I was trying unknowingly how to teach Neil how to read and he was learning.

**What the Holy Hell had I stumbled upon????**



**Neil Burke:  
The man who changed my life**

They said I could do that. So I did. I had taken care of the problem. I was in the clear. I had also zero expectations for Neil, but I'd done my job. And the surveyors would be pleased. So, I got the two classes, got the materials, didn't know what the hell I was doing, and began to work with Neil... And he began to learn....

**WHAT??????**

This was nuts!!!! As far as I knew, from what I'd been exposed to, what I'd learned, the window of opportunity for anyone ever to learn how to speak was up until the age of 4; and then, if it didn't happen, it wasn't going to; and, also, if a person had not been able to learn how to read, up until the age of 13, they weren't going to either. Neil was 35, and had never been to school.

So, that Saturday I walked out of the library, and practically ran across the street to the college bookstore and bought 17 books on how to teach 'normal' people how to read, and I read them all in the next 6 months. Meanwhile, back at the group home, I continued working with Neil. And as I worked with Neil, several other clients in the group home saw what we were doing and said,

**“HEY!! ME TOO!!”**

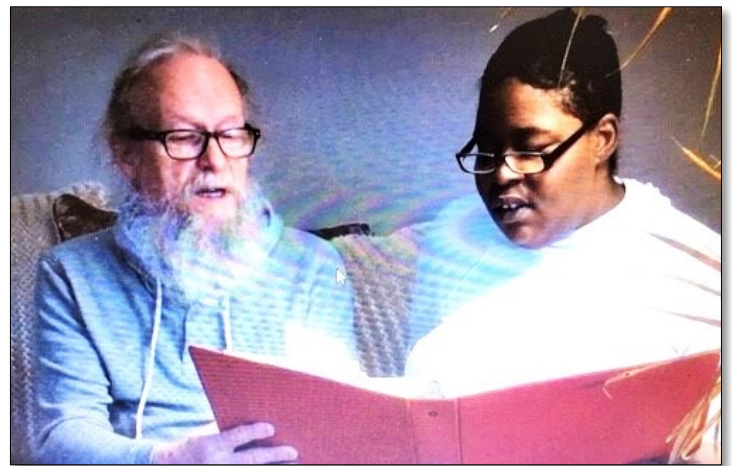
Within a short while, I had ten others that I began working with and most of them succeeded in beginning to learn how to read.

Our group home ISPs included folks from the County Board of MR/DD (now CCBDD) who worked at the adult training centers where our folks worked during the day. News got out quickly about what we were doing and by word of mouth, I ended up with others in the community whom I began working with. After I finished my Masters in Special ED multi-handicapped, I then did a Masters in Reading instruction, and connected with a CSU professor, Dr. Monica Gordon Pershey. We ended up speaking all over the country at academic conferences for more than 25 years, regarding the process of teaching folks with DD/ID how to read. At first, I used the Laubach materials (adapted) and then got permission from Harper Collins Publishers NY, to retype Charlotte's Web into size 28 Ariel font for easier visual accommodation. Since then, I have developed my own literacy curriculum, and now have a web site that is 100% free for anyone to use and share and download:



[www.literacyforanyone.com](http://www.literacyforanyone.com)

I have personally logged more than 10,000 hours in 34 years teaching folks with DD/ID how to read, taking many from zero literacy skills to independent reading abilities. And I did not initiate or envision any of this myself. I fell into it, with Neil Burke's help, and a whole lot of others along the way who paved the way for my doing this. And the folks I've worked with have been the ones who have taught me.



***Clockwise from top left - Simon, Tierra, Davis, and Alex – Just a few of the readers with whom I have had the honor to learn***



And by the way, Dr. Pershey and I were at an academic 3-day conference doing our literacy thing in Chicago in the early 2000s when I happened to also, for the heck of it, sign up to listen to a national advocacy organization's presentation.... Guess who!? VOR! and I joined their organization, then and there.



## Finding a New Home for Dale

By Lana Freeman

This is the story of my four-year search for a suitable home for my brother Dale, a man who faces significant intellectual disabilities and medical requirements.

Dale was born in 1963. He turned 62 last August, but his mental age is only that of a 3-year-old. Before Hurricane Ida struck in 2021, Dale lived in a group home in Thibodaux, La., operated by ResCare. After evacuating to North Louisiana, ResCare unceremoniously relocated him and the other men from his group home to a nursing home in New Iberia—a sudden change of environment that left them feeling abandoned and forgotten. ResCare left my brother and other men like him behind, treated them like discarded trash, and forced their families to grapple with the painful reality of finding appropriate care for their loved ones.

We later found out that ResCare had lied to us. They claimed that the hurricane damaged the house in Thibodaux and made it unlivable, which was false. After the storm, I visited the house to retrieve my brother's belongings and spoke with the homeowner, who confirmed that ResCare's statement was a lie. ResCare no longer wanted to provide medical care for my brother and the other men in this home, and they took advantage of Hurricane Ida to abandon them. How could this happen in today's world, right under the eyes of Louisiana's Office for Citizens with Developmental Disabilities (OCDD), without any accountability?

Our situation became an absolute nightmare. We spent the next four years in dire search of a proper group home where Dale could receive the 24/7 medical attention he so desperately needs. Dale is not physically disabled; he can walk and talk and deserves compassion and support. He has diabetes and requires insulin injections up to three times a day, yet no one seemed to care enough to help us.

I reached out to our local ARC here in Terrebonne Parish and every parish in Louisiana. I contacted the top ARC offices in the nation. I stayed in touch with the Houma OCDD, and every office I could find. I contacted my local and state representatives, and even reached out to the governor's office. Of all those contacted, only two responded, promising to forward my letters to the appropriate offices. However, this led me back to the Houma OCDD office, which has been unable to help us. It's been four years of frustration.

I became profoundly disillusioned with the support—or lack thereof—from the state of Louisiana. Despite our ongoing efforts to identify alternative group homes that offered the necessary medical care, we found a significant shortage of support services in the state. Our exhaustive search throughout Louisiana had yielded no results—no providers could offer him a home that would meet his medical requirements.

During all of this, the nursing home told us that they were no longer able to care for him. Throughout this ordeal, the entire staff at New Iberia Manor North Nursing Home had been the ONLY group to try to help us. Even though they could not keep Dale and had evicted him once before, they had truly been a Godsend, trying to assist us.

Last June, Dale was accepted into the Westside Habilitation Center in Alexandria, Louisiana. However, our relief was short-lived. I was soon informed that he would not be able to stay there because of his diabetes. He was hospitalized for the second time since he first arrived due to a heart rate of 145-150 beats per minute. They sent me a text to let me know that my brother had been taken to the hospital. Shortly thereafter, I received another message stating that he would not be allowed to continue at Westside once he was released from the hospital.

They had him wearing a diaper, helmet, and mittens. He was so stressed that he scratched his scalp raw. Shockingly, they put Dale back on Ozempic as soon as he arrived—even though records showed he'd already had terrible side effects from it earlier this year. His body couldn't handle the medication, so he was taken off it at New Iberia. Despite this, Westside kept Dale on Ozempic, even as his condition worsened. He stopped eating and was dying.

Finally, finally, I spoke with Casey Henry [Dufrene], who referred me to Terry Lafleur, the President of the Pinecrest Parents Association. Pinecrest an intermediate care facility for people like my brother in Pineville, Louisiana. Terry recommended I reach out to our state representatives again, this time about potentially getting Dale into Pinecrest. I spoke with Representative Rhonda Butler, who has a son with I/DD and who understood the immediacy of our situation. She helped us search for possible placements.

On August 12, Dale had two interviews: first at Pecan Grove in Alexandria, then at Pinecrest in Pineville. I attended both and finally learned Dale had been on Ozempic for weeks. Thankfully, that same day, he was taken off the medication for good.





grounds are decorated for Christmas and attract visitors from all over. They celebrate every holiday—even prom.

Dale has joined their day program, giving him a chance to enjoy fun activities. He can finally have the three-wheeled trike he's always wanted, parked right in his courtyard, and ride it through the park whenever he likes.

I'm sad that Dale is three hours away, but right now, it's truly the best place for him. We'll adjust, as long as my brother is cared for and loved the way he deserves. I've even made new friends along the way.

My family is very pleased to have Dale in Pinecrest Supports and Services Center and plans to stay. They saved my brother's life and have so much to offer him. It's been a dream come true for all of us.

The past four years have taken an enormous toll, but for the first time in ages, I finally feel at peace. I can sleep again, and I'm beginning to look forward to reclaiming my life. To everyone who has supported us—your kindness, encouragement, and willingness to help Dale have meant the world. We are truly, deeply grateful.

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## JAMIE LAFLEUR      By Terry Lafleur

Our beautiful daughter, Jamie, will be 47 years old December 16, it is hard to believe. Time goes by so quick. I was in the delivery room that day and remember she didn't cry like other newborns, and I remember seeing the doctor's reaction. Later that day the doctor came in and told us there was something wrong. Jamie had too much fluid mass in the front of her head. After that, it was one doctor visit after another as we kept trying to find answers.

This was very hard on us, our parents, and especially our two older kids. They wanted to help but didn't know how. We were told that we might want to look into placement for Jamie but we were not sure how to proceed. We met with several doctors who could not give her the care she needed, so we went to look at the facility they recommended. It was a very nice place, so we agreed.

Jamie did very well there for fifteen years, but this was not a residential facility at that time. We had to find another placement. We tried a community home not far from the facility. We liked it as it was very nice place, but Jamie could not adjust and her behavior got worse. One night she aspirated and spent two weeks in hospital ICU. She did recover after weeks and we brought her home to get better. At that time the community home called and told us not to bring her back. They were more concerned about their liability than her well-being.

About two months passed and we got a call from Pinecrest Supports and Services Center, an ICF in Pineville, Louisiana, also about an hour from us. We had not heard good things about Pinecrest and didn't feel like going, but we decided to look for ourselves. We learned very quickly that we were not given the right information. We were very pleased with what we saw. We decided to try. She has been there since February 2001. We can visit anytime and many times we just walk right into her home. I call every day to check on her. It is not perfect, never was, never will be, but **PINECREST SAVED JAMIE'S LIFE.**



## The Importance of National Advocacy

By Rita Winkeler

As a member of the Murray Parents Association (MPA), a family advocacy group for Murray Developmental Center, a state intermediate care facility in Illinois, I had been advocating at the state level for over twenty years, when I first learned of a national organization that could give me a voice on the federal level: VOR – A Voice of Reason.

Over ten years ago, the state of Illinois attempted to close Murray Center. Of course, the MPA advocated at the state level, visiting with legislators, and spreading the story about why closing the center was wrong, and would adversely affect those with developmental disabilities. A long time VOR member then introduced me to VOR. I knew immediately that I needed the help that only VOR could give me, and our group. VOR helped me understand the importance of not just advocating at the state level, but the importance of advocating at the federal level, where many of the policies and laws are enacted.

VOR gave me a quick lesson in why what the state was attempting was in violation of federal law. The MPA then started advocating at the federal level, meeting with our federal lawmakers. We learned then that one of these congressman's father worked at Murray Center at one time. Congressman Shimkus then wrote letters of support for us, and met with Illinois state legislators. Advocating at the federal level made a huge difference in the outcome of the attempt to close Murray, as the MPA became knowledgeable of the rights and responsibilities of the federal government that affected our individuals at the state level.

Since that time, I have continued to advocate at the federal level. Each year I visit Washington, D.C. with a VOR group and advocate not just with Illinois federal legislators, but with other disability groups. VOR keeps me informed throughout the year about upcoming legislative actions, which enables me to share these issues with my fellow MPA members. Whenever I have a disability issue I know I can pick up the phone and contact someone in VOR, and they can help me understand the issue better. I also can reach out to VOR members across the country, who may have experienced some of the same issues we are experiencing in Illinois. VOR members also reach out to me, and often working together we can resolve an issue affecting our loved ones with disabilities.



**With my son Mark, as he prepares for the Holiday Play at Murray Center**



**Meeting with members of the Department of Justice last spring at VOR's Annual Legislative Initiative: VOR's Katrina Robertson, Me, DOJ's James Fletcher, Bo Tayloe, & Victoria Thomas, VOR's Casey Henry and Peter Kinzler**

Advocating at the federal level has also enabled me to get to know my federal legislators at a personal level. I may not always get to speak directly with my congressperson, but I develop a relationship with their legislative assistants. This makes such a difference, as they know me as a person, not just a number. I can call and talk to them, and they are more willing to listen to my concerns.

VOR has made such a positive difference in where, when, and how I advocate for those with disability rights. Their knowledge has enabled me to make a difference, not just in Illinois, but in a small way a difference in federal issues that affect those with disabilities.

## Exploring Alignment in Advocacy

by Hugo Dwyer

I'm typing this on my laptop on the Amtrak Northeast Regional from Washington, D.C. back to NYC, as I reflect on a meeting this afternoon hosted by members of the Administration for Community Living (ACL). The topic of the meeting was "Exploring Alignment on Priorities" and it included representatives from several national advocacy organizations ranging from the Autism Self Advocacy Network (ASAN) at one end of the advocacy spectrum to VOR – A Voice of Reason at the other. It included the National Council on Independent Living (NCIL) and the National Council on Severe Autism (NCAS), ANCOR, the Autism Society, Autism Speaks, The National Association of Councils on Developmental Disabilities (NACDD), the National Association of State Directors of Developmental Disabilities Services (NASDDDS), the American Association for People with Disabilities (AAPD), CommunicationFIRST, Together for Choice (TFC), and the Arc.

I'd like to thank Mary Lazare, who now holds the title of Principle Deputy Administrator of the ACL for bringing all of these advocates together, in person and on Zoom, and trying to find common ground with one another and appreciate the range of issues that each of these organizations have set as their priorities. Remarkably, we found that we agreed on most of the issues that were presented. Or perhaps it was unremarkable, as everyone in the room and on the Zoom was there because of their concerns for people with intellectual disabilities and autism (ID/A).

I'd also like to thank Mary for opening the door for me to speak first, after she delivered her opening remarks. I had previously shared with this group an editorial I had written for the Autumn, 2025 edition of the VOR Voice, hoping the ID/A community would unite and stand up for all of our folks in the face of the Medicaid cuts that had been signed into law last July 4<sup>th</sup> in the One Big Beautiful Bill Act (OBBBA). A variation of that editorial appears on our website, and in the aforementioned edition of the VOR Voice. I felt it was important to establish that we needed to respect one another's choices and challenges first if we were ever to agree on our shared priorities for future advocacy. I then added that my priority for all people with ID/A would be to support our Direct Support Professionals (DSPs) and strengthen the caregiving workforce.

I was pleased when Jill Escher of NCSA spoke next, reinforcing some of what I had led with and adding her perspective as the mother of two children with severe autism. I was even more pleased, and surprised, when Katy Neas of the Arc continued in that vein added the need to improve dental care for our population. And it was even more surprised when Greg Robinson of ASAN agreed with what had been said, and added that we needed to address the needs of people with ID/A and co-occurring severe mental illnesses (SMI). Katy Neas, CEO of the Arc, spoke of the need for dental services for people with I/DD, an issue VOR has been involved in for years. Jordyn Zimmerman spoke, by typing into her iPad, of the need to invest in communication systems for people with autism. And Ashley Kim Weiss of Together For Choice spoke in detail about the problems caused by the Settings Rule. There was a remarkable sense of harmony among these diverse participants. Each of these themes rang true.

While there was some talk about the importance of HCBS and deinstitutionalization and "everyone does better in the community", that rhetoric mostly took a back seat to discussing more actionable ideas.

I hope that Mary and the ACL follow through with more of these meetings. They have the potential to bring together forces that have been at odds with each other to the detriment of our shared goals.

*(P.S. There will be a quiz on Monday on all of the acronyms cited above.)*

### What Does Community Really Mean?

As mentioned above, some advocates continue to speak of a preference for "community-based settings" as different from Institutional settings. But what is community? What does that really mean?

As Mary Lazare pointed out in her opening remarks, everyone has heard stories about how residents of small group homes in community settings often feel isolated, especially when they feel shunned by their neighbors. And as we have often emphasized, an ICF or a sheltered workshop can provide a sense of belonging, of camaraderie and community that can only be found in the company of one's peers.

To me, community has little to do with physical location, of a type of building, of a rural, suburban, or urban setting. Community is a state of mind. It is finding an environment in which one may thrive, in which one may feel safe, and in which one can interact to the best of their ability.

I live in a city of 8.5 million people. My earliest childhood friend lives in eastern Maine. His closest neighbor lives 10 miles away. Is one of these settings more of a community than the other? Or are they both communities because these are the settings in which we each feel most comfortable, where we feel that our various physical, emotional, and spiritual needs are met?

When an individual is placed into any setting, the idea of community is a matter of their reaction to their environment. Do they feel accepted, or do they feel isolated? Do they interact with people like them? Do they interact with people not like them? Are they among people they want to be with, or do they long for a different setting?

This is what we mean when we say that an ICF *is* a community, or that it may feel like a community to some, but not all, individuals. This is why we speak of choice. Individuals should be able to make this choice, without having government agencies or advocacy groups imposing their own ideologies upon them. Families and guardians should be able to determine which environment works best for their loved ones who lack the capacity to choose for themselves.

## Another Reason Why VOR Matters to Me ....

By Joanne St. Amand

VOR empowers me to speak up for all individuals with intellectual disabilities and autism. I cannot say enough about the guidance, information, and support I received over the years from members of VOR. So many of the people I have met over the years have become friends-for-life, and some of them have become even more – they've changed my way of thinking, my sense of caring, and my approach to my own personal journey through this life.

About a year ago VOR lost one such member. She was Jill Barker, a wonderful, effective, articulate, knowledgeable and passionate board member, mother, and friend. She was the mother of two young men, Danny, and Ian, both with severe intellectual disabilities.

Jill was one of the first people I met when I joined VOR over 25 years ago. She was an important mentor to me and many others. By her actions, Jill taught me to be gentle, yet firm when talking with administrators in federal agencies such as the Centers for Medicare and Medicaid Services (CMS). Jill always did her homework and was well prepared for meetings which she participated in frequently. Even now Jill continues to educate me and others in the legacy she left us .... her "DD News Blog." (link: <https://theddnewsblog.blogspot.com> – or use the QR code at the bottom of the next page)



Jill Barker

One such blog entry is on "In Defense of Complainers" where Jill quotes Sarah Kendzior who writes "*The surest way to keep a problem from being solved is to deny that problem exists.*" ([The DD News Blog: In Defense of Complainers](#)). In this blog Jill gives us several points to consider when we join the ranks of the complainers. She says, "**Complaining to expose problems and bring about change is a good and noble pursuit, but the question of how to complain effectively to resolve problems for the benefit and satisfaction of a disabled individual is more complicated.**" Jill adds, "**All too often we allow others to complain for us.**" She warns "**Professional advocates may be eager to step into that role, but sometimes they may have their own agenda that conflicts with the needs of the person with a disability.**"

Jill encouraged parents and guardians that .... "**at the core of any good complaint is the experience of the person who has been wronged.**" Jill gives us points to consider when we join the ranks of the complainers and advises us "**Don't Give Up! You may not get what you want immediately, and you may feel like there are too many barriers to resolving a problem considering the time and effort you are putting into it. But in the meantime, you are way ahead in figuring out what makes the system of services for people with disabilities tick and what you need from it. These efforts are never wasted.**"

In another of Jill's Blogs, possibly showing a bit of foreshadowing of issues expected with the roll out of the One Big Beautiful Bill Act, Jill writes the blog entitled "[The DD News Blog: Medicaid "Unwinding" Breeds Chaos in States.](#)" Here Jill talks about the hours people have waited on hold trying to get help with renewals, with some waiting as much as three hours. Jill speaks about one parent, Donna Guyton, who said in a court filing that Tennessee's Medicaid program, called TennCare, sent a June letter revoking the coverage of her 37-year-old son, Patrick, who had been eligible for Medicaid because of disabilities since he was 6. As Guyton made calls and filed appeals to protect her son's insurance, he was hospitalized with pneumonia, then spent weeks there before dying in late July. TennCare said in a court filing Patrick Guyton's Medicaid coverage was never actually revoked — the termination letter was sent to his family because of an "error".

Even Jill's son Ian, who has profound, lifelong disabilities, and lives in a group home in Ypsilanti, Michigan, was found ineligible for full Medicaid healthcare benefits that he had been receiving for almost 20 years. [The DD News Blog: Missteps by the Michigan Department of Health and Human Services in "unwinding" Medicaid eligibility.](#) Jill was able to eventually resolve it but warns "**Gaps in coverage can jeopardize people's access to health services or their financial security if they get medical bills for care they cannot postpone.**"

One of my favorite is Jill's blog "[The DD News Blog: Surviving the Inclusion Delusion: Danny at 40.](#)" Jill defines the term "**Inclusion, when applied to schooling for disabled children, is the belief that all children, regardless of the severity or nature of their disabilities, can and should be educated in regular classrooms with their non-disabled peers.**"



*Danny*

Jill asks, *“Is it right to make judgments about “all children with disabilities” without considering their individuality and acknowledging the full range of their diverse needs?”*

Jill writes, *“I pondered how would Danny be accommodated in a regular middle school classroom? How would they deal with his bouts of vomiting after meals, the necessity for frequent diaper changes, and his need for floor space for his favorite activity - rolling over? Would other students and staff tolerate his occasional blood-curdling screams when things weren't going well for him? Was it wise to remove him from an environment that had every accommodation that he needed and place him where virtually nothing was geared toward his needs?”*

*Could anything prevent him from*

*becoming the chief source of disruption for almost every activity that normally occurs in a typical classroom?*

In this one Jill poses realistic situations regarding her son Danny and asks common sense questions in such a way as every one of us with lived experience gets the point .... but probably not the others.

In Jill’s own words, *“Thanks to Danny (and Ian who came along eight years later), my blog has been an attempt to set the record straight, give a voice to people who are rarely heard, and attempt to restore some balance in the stories that are told about people with disabilities. This is an unbelievably frustrating time for families who see their judgement questioned at every turn as they attempt to salvage necessary services for their love ones and hope for a truly inclusive future that acknowledges differences in abilities and needs and honors the choices that families and their loved ones must make.”*

I recommend all of us to revisit Jill’s blogs, especially when we need advice and inspiration. Jill was amazing, I thank her for the wisdom she installs in us, and I miss her dearly.



*Ian*

*- Joanne St. Amand, President, December 8, 2025*



*Homepage of the DD News Blog*



*In Defense of Complainers*



*On Lake Michigan with baby Danny*



*Unwinding Medicaid Eligibility*



*Danny at 40*

## Bringing Ministry To Erica

By Ann Knighton

My daughter, Erica Streetman Knighton, is 57 years old. She is profoundly developmentally and intellectually disabled, due to a chromosome error – a translocation of the 8<sup>th</sup> and 22<sup>nd</sup> chromosomes. She has a seizure disorder, osteoporosis, and kyphosis. She suffers from hypothermia, and requires a feeding tube for all of her meals. Erica benefits from living in an intermediate care facility, Gracewood, in East Central Georgia.

Gracewood provides for all of Erica's physical, medical, and psychological needs. One day, I was speaking with my pastor, Rev. Dr. Shirley Rivers, and she suggested that the **whole person** needs to be ministered to - not just not just the physical body, but also the soul of the person, the real part of the person, the inner person. We had brought Erica to church services before, but my pastor suggested bringing services to Erica. I have always been very involved in the Church, and I was thrilled at the idea.

It took a lot of preparation, more than I had imagined. I talked to the facility administrator at Gracewood. At first, she said that we could do it, so I made arrangements to bring a lot of people to Gracewood for the service. But then the administrator changed her mind, saying it wouldn't be fair to people of other religions. I asked if I could bring a smaller group, and she decided it would be okay. So now I had to tell some people they could come, and hope that the others understood why they were no longer included. I didn't want any hurt feelings. This was to be a joyous occasion.

So on May 31<sup>st</sup>, several members of the First Dayspring Baptist Church came together at Gracewood to minister to Erica. It was a time of praise with prayer and scripture and a message of hope by the Pastor Emeritus, Dr. Willie R. Rivers, entitled, "One day Erica will have a hop, skip, and jump!". This was a time of sharing about Erica, after which the Congregate performed a closing hymn, and Pastor Rivers gave the closing prayer.

I was touched. It was a beautiful celebration, and a very special time of fellowship. I would like to thank all those from the Church, including Rev. Susie McCall, Deaconess Mary Dawson, Sister Mamie Rosse, two members of the recreation staff, Erica's nephew Deacon Brandon Batchelor, and all of the staff and administration of Gracewood who helped in facilitating this celebration. They didn't just minister to Erica, but to me, and to everyone who participated in the afternoon service.



## **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 organizations 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.

Senator Maggie Hassan (D-NH) and Representative Brian Fitzpatrick (R-PA) have re-introduced the “Recognizing the Role of Direct Support Professionals Act” (S.3211/ H.R.6137). in the 119<sup>th</sup> Congress. Sen. Hassan managed to get this bill through the Senate in the previous congress, but it failed to make it through the House. With the new congress, we have to start all over again. This term, we want to see it make it through both chambers and pass into law. That’s going to take a lot of work.

Please reach out to your Senators and members of the House of Representatives, and ask them to sign on to these bills.

S.3211 - [www.congress.gov/bill/119th-congress/senate-bill/3211](http://www.congress.gov/bill/119th-congress/senate-bill/3211)

H.R.6137 [www.congress.gov/bill/119th-congress/house-bill/6137](http://www.congress.gov/bill/119th-congress/house-bill/6137)

## **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 73 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](mailto:hdwyervor@gmail.com)

or go to <https://www.vor.net/get-involved/donate-to-vor>



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

## Happy Holidays!

We wish everyone a very  
Merry Christmas,  
A Happy Hanukkah  
&  
May all your needs be met and  
your wishes be granted  
in the  
New Year!

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>

Thank you for your dues and contributions!

I would like to give a gift membership to:

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TELEPHONE \_\_\_\_\_ FAX \_\_\_\_\_

TELEPHONE \_\_\_\_\_ FAX \_\_\_\_\_

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EMAIL \_\_\_\_\_

MY CONTACT INFORMATION HAS CHANGED

- \$45 per year per individual;
- \$200 per year per family organization
- \$250 per year per provider / professional org.

To make a memorial or honorary donation, please visit our website at:  
<http://www.vor.net/get-involved/donate-to-vor>

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

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

\$2,500     \$1,000     \$500     \$250     \$100     \$50     Other \$ \_\_\_\_\_

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

Card Number: \_\_\_\_\_ Expires: \_\_\_\_\_ / \_\_\_\_\_ CVC (3-Digit Security Code): \_\_\_\_\_

Signature: \_\_\_\_\_

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