

NYADD-VOCATE

Families Matter: Speaking Out For Loved Ones With Developmental Disabilities

NYADD FOCUS - Spring 2025 Announcements

* This weekend, Saturday, May 3rd, in Utica there will be an Autism Walk. NYADD will be represented at the Walk with a table of information, including the NYADD one pager and the NYADD newsletter. Come stop by to meet fellow NYADD members. Regional Lead Steve Gonyea will be there greeting families. Sponsored by the Kelberman Center.



* NYADD will be represented at the New York State Assembly's annual Legislative Disability Awareness Day (LDAD) on Thursday, May 8th in the Well of the Legislative Office Building in Albany, NY from 9am to 2pm. LDAD is held annually to inform legislators and the public about disability issues and to recognize the achievements of people with disabilities in New York State. In addition to the exhibitor fair, LDAD will also consist of an opening ceremony and the presentation of a legislative package. All members are welcome to join our NYADD table and represent our loved ones.

* OPWDD- Acting Commissioner Baer Announces Task Force On Aging with I/DD
<https://opwdd.ny.gov/news/new-commissioners-taskforce-aging>

* OPWDD Announces Office of Advocacy-
<https://careers.goadvancedenergy.com/companies/new-york-state/jobs/39375199-director-of-advocacy-services>

* NYS Justice Center announces new Acting Executive Director Maria Lisa-Murray. Additionally, an available position within the Justice Center was announced. Applications were recently accepted for the Justice Center- Associate Counsel (Director of Intergovernmental and Legislative Affairs (deadline was 4/23)

* DDAC (Developmental Disabilities Advisory Council) If you missed the April 9 meeting, you can view it here: <https://opwdd.ny.gov/developmental-disabilities-advisory-council-ddac> The next meeting is July 22 at 11am. Please remember, there is a new system, so if you would like to speak publicly, you need to identify this when you register for the meeting. Register here:
<https://opwdd.ny.gov/event/developmental-disabilities-advisory-council-ddac-meeting-0>

NYADD – CDPAP Update

NYADD thanks State Lead **Heather Boroughs** for her tireless advocacy for the CDPAP individuals, families and caregivers and wish her luck as she moves on from NYADD into her future endeavors advocating for families. While many issues around CDPAP continue to need resolution, we appreciate her advocacy, as well as other organizations who have collaborated with NYADD members for support.

There were many spirited posts and conversations on our main NYADD page regarding CDPAP and it was determined that it was best to provide a place where these voices and advocacy could come together to give and get the information needed for all of the involved families. After the first "deadline" came (and went) on April 1, NYADD created the "NYADD Focus Group- CDPAP". Currently with over 800 members, the Focus Group has been helpful to many and will continue as a NYADD priority.

NYADD – Regional Lead steps into Legislative Liaison role

By Shannon LaVigne Regional Lead (Region 5)

Hello NYADD members,
I'd like to take a moment to introduce myself. My name is Shannon LaVigne, and I've had the privilege of serving as a NYADD lead for the past two years. Recently, Katy asked me to take on the role of Legislative Liaison for NYADD — a role I am both honored and excited to accept.

A little about me: I am an educational advocate, a member of my school district's SEPAC (Special Education Parent Advisory Council) board, and, most importantly, the proud parent of three amazing children — one on the autism spectrum and one who is medically fragile.

When Katy asked me to step into this role, I was eager to bring my passion and skills to help further NYADD's mission: ensuring families and self-advocates have seats at the table. Far too often, the voices of families and individuals directly impacted by disability policies are left out of discussions and decisions that shape the programs and legislation affecting the ID/DD community in New York.

This year, I have been hard at work advocating for several important initiatives, including:

- The Blue Ribbon Commission Bill, fighting to ensure family and self-advocate input is included,
- The Ombudsman Bill, pushing for independent, transparent reporting
- Assemblymember Paulin's Camera Bill, which would allow video and audio monitoring in nursing homes and assisted living facilities — a critical measure for our community members who, due to aging or increasing medical complexity, find themselves in these environments.

I'm excited to continue this work and look forward to collaborating with all of you to make sure our community's voices are heard loud and clear.

I am proud to help bring NYADD's mission of seats at the table to life so that our voices are truly heard.

Warmly,

Shannon LaVigne

Legislative Liaison, NYADD



NYADD – On the GO

Why I became a Regional Lead

By Rita Jones-Safian Regional Lead (Region 5)



My son, Daniel, who has profound autism, is 25 years old and transferred from a Children's residential placement to an adult placement in Feb. 2023. He is minimally verbal, can be aggressive and self injurious and will need 24/7 care for the rest of his life most likely. At his former placement, where he was for 8 & 1/2 years, he had the services and supports needed to have a quality life.

A healthy lifestyle was promoted which included excellent nutrition, movement and a sensory diet. Speech therapy and OT Therapy were delivered 2x a week. He used his AAC device as one way to communicate when people couldn't understand what he wanted or was saying. He had a day program he attended 5 days a week which prioritized nutrition and movement and he engaged in barn and farm chores, animal care and cooking. He was productive and felt good about himself. He also received state of the art medical care and was amenable to going to the dentist and getting other diagnostic tests and procedures as needed.

Fast forward to today, when he first moved to the adult program, I was excited that he would be closer. Little did I know he would fall apart. The supports he had vanished, and my son went into full blown crisis. Looking back now it doesn't surprise me. My son, one of many tens of thousands similar to him, has complex behavioral and medical needs and is not receiving the quality and level of services he had in the past.

My mission as a Regional Lead for NYADD is to advocate for all of those who cannot advocate for themselves in every way needed and be part of the solution. My son and others like him deserve a quality life filled with purpose.

NYADD Regional Leads On the Move:

Steve Gonyea (Region 2) attended and spoke at The National Council on Severe Autism conference in Washington DC. He also visited many Representatives' offices.

Simcha Weinstein (Region 4), under the Jewish Autism Network, received a grant from CSS IDDO to inform families about the new Independent Ombudsman program.

Ellen Alexander (Region 5) attended the SomaRPM international conference in Austin, Texas in March. The conference included presentations of ways to improve methods of helping autistic individuals, who were part of the conference, along with two presentations on current research.

<https://www.halo-soma.org/detalles-y-registro/halo-rpm-annual-conference-2025>

Katy Faivre (Region 3), is representing NYS Council for Developmental Disabilities, is attending National Aging with Developmental Disabilities Conference and the National Council for Developmental Disabilities National Conference on Aging with DD in St. Charles, Missouri.

<https://www.agingwithdd.org/conference/>

Linda Molina (region 3) is taking a lead role with **Shannon LaVigne** (region 3) and Rep. Missy Miller, growing the families for parent paid caregivers (NYS) Facebook page and the Medically Fragile of NY (VMFNY) along with several other parents.

Rita Jones-Safian (region 5) is taking the lead on creating and spreading the word on a new [NYADD LinkedIn page](#). We invite every NYADD member to join us on [LinkedIn](#) and be part of the community there.

Heather Walters (region 3) is participating in LEND as a Family Specialist, researching the transition of care from home to the ER for adults with disabilities, looking at information from family members, group homes, Emergency medical professionals and group home workers.

Shannon LaVigne (region 3), along with actively advocating for CCA for the medically fragile, she serves on her local (Albany) SEPAC Board, where she recently participated a panel discussing Autism in schools.

NYADD – The Family Circle - Certified Housing and Video Monitoring Priorities

Many NYADD members who have loved ones living in certified residences have brought their concerns of diminishing advocacy in established organizations for people living in certified residences (group homes). NYADD created a Family Circle with over 100 members that focuses on discussions related to what they see as the good and the bad of those settings. They are working to collaborate with suggestions and to find solutions. We believe that concerns of quality of services, health and safety issues are being overlooked and often dismissed, and that transparency in times of trouble or crisis is not evident.

Other concerns discussed included a need to improve the day-to-day communication and interface at homes, between both families and staff. Often families never know the other family members and are told that contact information cannot be shared, rather than allowing families to collaborate and support the home and the agency.

From our Certified Housing Family Circle, two other initiatives have emerged. Due to the many health, safety and incident management issues that families brought to the Housing group, our Video Monitoring work group was created. This group of family members has met to discuss needs and suggestions from incidents that they have experienced. We have discussed what options might be available through legislation, including Cameras in Common Areas (<https://www.nysenate.gov/legislation/bills/2025/S3715>), as well as amending the current ADM which allows video monitoring in a group home if approved by the clinical team.

https://opwdd.ny.gov/system/files/documents/2020/01/video_monitoring_adm.pdf .

The last meeting included Anil and Shalini Babbar who shared their devastating story of their son's abuse at his residential school, along with a fascinating tech development for observing and training.

NYADD brought these concerns to our representatives and met with our Disabilities Committee Chairs Assemblyman Santabarbara and

Senator Fahy who support these initiatives. Assemblyman Santabarbara agreed to meet with NAYDD Regional Leads to discuss the need and strategies for video in common areas in group homes.

NYADD has also been working with Assemblymember Amy Paulin, Chair of the Health Committee, on the bill for Cameras in Nursing Homes and Assisted Living Facilities. NYADD has written a letter of support for this bill, as there are many children and adults with I/DD currently living in nursing homes in NYS.

<https://www.nysenate.gov/legislation/bills/2023/A4616>

We invite families to join our next Family Circle on certified housing on May 29 at 7pm. Please email NYADDStrong@gmail.com, attention Katy Faivre, subject: Certified Housing

NYADD – A Spelling Journey

Ellen Alexander is one of our prized NYADD regional leads. Ellen has been a trailblazer in the developmental disability community for many years. Ellen's son, Alan, is now 56 with a diagnosis of autism. Let's time hop back to 2009 to Alan as a 40-year-old young man. He received the education typical of that time, and unfortunately, he remained nonverbal and unable to communicate with his family. Misunderstood and underserved.

As many of us have done, Ellen was still searching for ways to assist her son. Around that time, she learned about Soma Mukhopadhyay, who had taught her own autistic son, Tito, to spell and communicate through what she called Rapid Prompting Method (RPM). After years of being told that Tito could not learn, Soma had developed her own methods for her son and then began to teach other children who could not communicate.

Ellen and her husband, along with some other families, were so convinced that they wanted their children to work with Soma that they hosted a 4 day workshop on Long Island. Alan had the opportunity to work with Soma for 40 minutes each day. The spelling was slow and laborious because at that time, Soma used primitive materials to be able to offer the

needed letters to the speller. (Soma later invented letterboards that look more like what we see today.) Nonetheless, at his last session of that 1st workshop with Soma, Alan spelled out, "After I turned 30, I realized that I had forgiven God."

Buoyed by that incredible insight, Ellen booked sessions at 4 day 'camps' held by Soma in Texas 2x a year for quite a few years. The group of families in Long Island began to host Soma 6 times a year to work with families and their Loved Ones. These sessions continue and are available to others by contacting rpmlongisland@gmail.com.

From slow beginnings 16 years ago, recently at a session with a trained communication partner, Alan wrote about liking his job and wanting to help other disabled people find work. And just a few weeks ago he wrote this poem, one letter at a time with a communication partner.

By Alan Bruce Alexander 3/4/2025

**Before stars the sky was dark
Even the moon was black.
Each night singing rays of sun
Would reach for the heavens.
Sometimes halos of sun
Got stuck in the night sky.
They began to shine.
The stars lit the sky
Creating diamonds of sparkling light.
Dark times will come and go
But never forget,
Brighter days are on the way.
The stars will shine again.**

Today Alan continues to hone his skills with Soma and other RPM practitioners. He spells about the frustration of being locked up in his mind before he began to spell and many conversations filled with deep insight. Recently he was able to ask his niece about her college plans and encourage her as she is struggling to make decisions. "Find out what makes you feel happy and you can't go wrong." Amazing advice from a non speaking autistic Uncle to be able to impart.

Alan is now learning to speak using techniques that Soma has refined to help nonspeakers further communicate. He can now call his family and participate in family zooms, and he is working on

texting skills. These are things his family never thought were possible.

For Ellen and her husband, they have had to revamp their responses to Alan. No more underestimating the depth of his knowledge. Now they hunt for ways to help him in this new world where he has so much to contribute. From supporting his blossoming speech to helping him use the letterboard, Mom and Dad are catching up to Alan

Ellen's message is that it is never too late to start spelling. Alan was 40 and has come so far. The children who start earlier can have so many opportunities unfold for them. Ellen and Alan would tell you, don't wait to start your own spelling journey with your child, no matter their age!



Please click on the picture to be able to view a video of Alan spelling with Soma.

If you are ready to investigate Soma RPM or another spelling method for your nonspeaker check out these resources:

[Halo-soma.org](https://halo-soma.org)

The link for I-ASC (International Association for Spelling) is <https://i-asc.org/>

There are Spellers Centers in San Diego, Atlanta and Tampa. <https://www.spellers.com/san-diego>

There's also their non-profit which is the Spellers Freedom Foundation

<https://www.spellersfreedomfoundation.org/>

NYADD – Connecting with CDD: NYADD Regional Leads Joining the Strategic Plan Focus Group

By Simcha Weinsin: NYADD State Lead

As the New York State Council on Developmental Disabilities (CDD) starts shaping its 2027–2031 Strategic Plan, NYADD Regional Leads were invited to participate in a special focus group to bring forward the real concerns we hear from families across the state, and the experiences we live every day as parents, caregivers, and advocates.

For those who may not be familiar, the CDD is part of a national network of councils created through the Developmental Disabilities Assistance and Bill of Rights Act. Their mission is to enhance the lives of New Yorkers with developmental disabilities and their families by promoting self-advocacy, inclusion, and innovative pilot projects. You can learn more about their work at <https://cdd.ny.gov>.

Regional Leads from across NYS participated including Peter Zummo (Region 1) Steve Gonyea (Region 2) Linda Monila and Katy Faivre (Region 3), Simcha Weinstein and Marilyn D'Agostino (Region 4) Ellen Alexander and Rita Safian (Region 5) along with Lucille Rossi from WIHD, led by Jennifer Goldman, Legislative Liaison for CDD and Kristin Proud, Executive Director, CDD. During the discussion, several key themes came forward loud and clear:

- **Housing and Aging:** Families stressed the urgent need for more safe, supportive residential options, especially as loved ones transition out of school or children's services.
- **Systems Navigation and Access:** Service systems are still complicated and overwhelming, particularly for families who face language barriers, have complex needs or don't know how to access OPWDD services.

Staffing and Continuity: Chronic staffing shortages and high turnover as well as inadequate training and experience continue to leave families struggling to

find consistent support along with concerns of abuse, neglect and overall quality of care.

- **Early Intervention and Education:** Participants highlighted the need for better early intervention pathways and caregiver education from the very start — beginning in hospitals and pediatric care.
- **Mental Health and Co-Occurring Needs:** Families called for better recognition and support around individuals with I/DD and mental health needs, especially in historically underserved populations, specifically for those with profound autism.
- **Family and Guardian Involvement:** Stronger and more transparent communication and case management with families, guardians, and individuals was emphasized as essential — not just during crises, but throughout daily life.
- **Linguistic and Cultural:** Families pointed to the urgent need for better outreach and culturally responsive services, especially for non-English speaking communities.

Despite the challenges, the group also shared a hopeful message. There are areas where New York has made real progress, including stronger early intervention programs, more inclusion efforts, and an increasing commitment to putting family and self-advocate voices at the center of decision-making. NYADD is proud to continue raising family voices and working alongside CDD to build a better, more inclusive future for all New Yorkers with developmental disabilities.

NYADD – Create a Way

By Steve Gonyea, Regional Lead (region 2)

On January 3rd, 2025 the Utica Center for Development Better Together Recreation Center for Complex Care, Disabled and Profound Autistic Individuals held a Gala fundraising event. This event was to raise funds to create a unique one-of-a-kind Center where everyone with any type of disability and every need will be welcomed, supported and included.

The Gala was a huge success. So many local businesses and community members stepped forward to support this vision which can impact the

lives of so many. Clearly this dream has caught fire in the community.

This out of the box Recreation Center is being built inside of a Church. It is a huge complex that will include sensory rooms, disability staffed snack bars, individual work/play areas with electronics and headsets in compartment style areas for privacy. There will be game rooms and unique visual and audio rooms as well as a music room. The Center will also include a restaurant style kitchen and ADA bathrooms with showers. There will be many more activities geared towards offering choices for every individual walking through the door.



Currently we are in the construction phase. The ADA bathrooms and showers, HVAC, electrical, carpeting have been put in, and the painting is being finished. Equipment and items for The Recreation Center are going to be ordered shortly.

Part of what makes this endeavor unique is that it is a grassroots and bootstraps project. We are creating our dream without state and federal dollars right now. All money used so far is from donations, meaning that every person invested in our vision counts and makes an impact! We are making progress towards our goal! We hope to open parts of the Center in September or even sooner if possible. It's a compelling story about how a group of parents came together to make something like this happen.

We expect the Center to be fully open by the end of this year. UCD (Veterans Outreach Center) have provided their own staff and veterans to help restore this church, converting it to this groundbreaking Recreation Center. It is a true community effort for the benefit of our Loved Ones. Our local families are so excited to see this endeavor happen where their family members will have the opportunity to access a

supportive environment and the opportunity to forge new friendships.

Our ultimate vision is to see other parts of the state mirror what we are doing. Please feel free to reach out to me for further information and creation strategies for your area!

Together we can create change!



The church housing the Recreation Center

NYADD and the Justice Center – Building a Safer System



Since 2022, NYADD has partnered with the Justice Center to strengthen systems that protect individuals with developmental disabilities. In a recent meeting, both parties reaffirmed the importance of structured, recurring conversations to elevate family voices and promote systemic improvement. The Justice Center welcomed NYADD's organized agenda and suggested future meetings include OPWDD's QA division to help resolve cross-agency concerns more effectively.

A few key priorities emerged from the discussion:

1. Strengthening Abuse Reporting.

There's a growing need for better clarity and categorization in abuse investigations, especially when

reports are labeled "unsubstantiated." Families often feel left in the dark - particularly when injuries are unexplained and individuals are nonverbal. It is essential that the process of flagging and tracking cases is improved.

2. Expanding Access to Video Footage.

Video surveillance often plays a critical role in uncovering the truth. While the Justice Center supports its use, they're limited by federal Medicaid rules. NYADD proposed new ways to track when video is submitted and how it impacts investigations—possibly through a checkbox on reporting forms and improved data collection. OPWDD's position remains unclear, and NYADD will continue to explore options.

3. Closing the Loop with Families.

When abuse is reported repeatedly, but remains "unsubstantiated," there's often no clear next step. The Justice Center may recommend retraining, but enforcement rests with provider agencies. NYADD raised the idea of requiring every agency to appoint a **Chief Family Advocate**, similar to roles at CCOs, to help families navigate these gray areas.

4. Ensuring Accountability for Reassigned Staff.

A persistent concern is the quiet reassignment of staff accused of abuse. NYADD emphasized the need for more transparent internal processes, stronger oversight when leadership is absent, and creative solutions—such as family volunteers or temporary staffing pools—to avoid risky coverage decisions.

5. Raising the Bar on Oversight.

Repeated violations by the same agency raise the question: can an agency or individual residence lose certification? NYADD will explore a higher tier certification system and seek clarity on how COMPASS status is awarded and maintained. The group also discussed whether this kind of agency history is accessible via FOIL.

Additional notes included the need for consistent attention to alternative communication methods (like AAC and letterboards), shorter and more family friendly JC forms, and timely follow-up—since families often wait longer than the promised 21 days for updates. The Justice Center's past work on choking hazards was cited as a strong example of responsive action that NYADD hopes to see replicated.

Moving forward, NYADD will continue to raise family voices and push for practical, systemic improvements that increase safety and accountability. We welcome continued dialogue with the Justice Center and OPWDD, and are encouraged by the potential for cross-agency solutions that work for individuals and their families, not just the system.

NYADD – Delving into the Ombudsman program (Ombudsprogram)

By Susan Havko, Regional Lead (region 3)



Ombudsman may be an unfamiliar word to many of us. What exactly does Ombudsman mean?

Ombudsman is from a Swedish word meaning representative. It includes areas of advocacy, education, mediation, and referral.

This new to NY state program is authorized under Mental Hygiene Law § 33.28 which mandated OPWDD to create one entity to provide an independent and impartial representative to help families resolve complaints, issues, errors or conflicts for those receiving OPWDD services. “The mission of the Ombudsman is to act as a resource and advocate for individuals and families as they navigate OPWDD’s programs and services”

The Ombudsprogram officially began in December 13th of 2024. Their main goal has been to educate parents about services that they may not be aware of, help them to advocate for their child thereby empowering them to advocate themselves for their child now and in the future. Some of the families reaching out to the Ombudsprogram already have services, but they may not understand how to fully navigate and utilize those services.

Flor Ramirez is the supervisor of the program. She herself has a young son on the spectrum and despite her knowledge and background as a lawyer and being accustomed to pushing back against

obstacles, it took 3 years for her son to receive services.

Like Flor, all of the people that you might encounter when you call the Ombudsman line or visit their NYC offices, have personal life experiences with disabilities. There are 6 staff answering the helpline and outreach partners all over the state in each of the DDRO regions. The helpline staff receive ongoing training to ensure the quality of responses to those in need.

Since December, there have been almost 350 calls to the Ombudsprogram. Most of these cases are complex and require ongoing assistance for months. The calls coming into the program seem to indicate that many brokers and CCOs are not helping families understand how to navigate the system. The Ombudsman can help families to fill that gap and understand the system better. The Ombudsprogram have helped many families by gathering information for them, gaining an understanding of what has been attempted previously, advocating for a client and asking for change.

So far, families who have utilized the Ombudsprogram services have responded very positively, even when the Ombudsman has had to clarify to a client that they don’t qualify for OPWDD services. There is a survey available after services every helpline call. Currently there is 4.8 rating because the Ombudsman have been able to resolve issues and clarify needed steps for families.

If you find yourself or your Loved One in a situation where you need the guidance and assistance of an Ombudsman, reach out today.

For help
contact our
statewide
helpline



IDDO has a helpline that is open Monday-Friday 9AM-5PM.

Staffed by:

- 5 IDDO Counselors
- 2 IDDO Attorneys

The helpline serves all of New York State

Call 1-800-762-9290

Email iddo@cssny.org

Contact form

<https://www.cssny.org/programs/entry/iddo>

Services that IDDO can provide

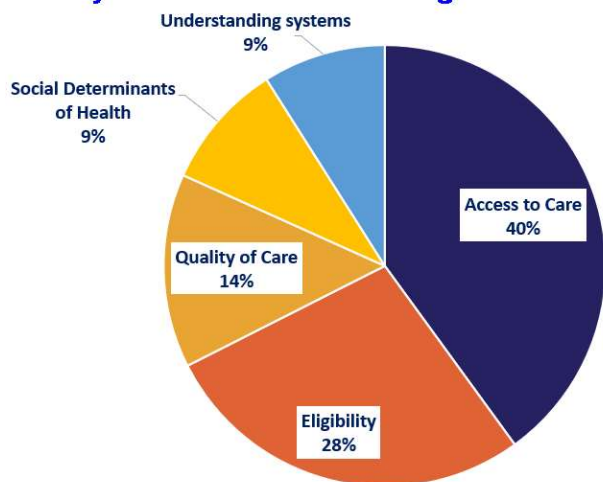
- ✓ Educate on OPWDD eligibility and the Front Door Process
- 🏠 Explore certified and non-certified housing options and mediate certified housing disputes
- 📄 Explain how to get necessary assessments and documents
- 👤 Answer questions about the role of the CCOs and care managers and mediate disputes
- 🗺️ Navigate self direction and other home and community-based services
- ⚖️ Advise on Fair hearing and due process rights and provide referrals to legal services as necessary

have profound autism. One is on a waiting list for an evaluation and another one is a trauma based teen whom we are adopting. The trip was worth maneuvering through each obstacle and every minute of effort.



One of Steve's sons in front of the capitol

Why are families calling IDDO?



Was it challenging? Yes! Especially with a 7 1/2 hour drive! But these kids were able to hear me speak at the Capitol with multiple Senator's offices on their behalf and other children like them! They heard me fighting for their needs and rights, which was so fulfilling to me. They got to see a parent advocate and the fight for supports and services, and to hear the request to change the broken systems they currently are in.

We were able to meet fellow disability parents and disability State Chairs and Vice Chairs across the country. This face-to-face contact is changing the way advocacy is done and planting seeds for the future!

I handed out our NYADD one page flyer and my card. I met with Senator Schumer, Senator Gillibrand, and Congressman Mannion's office. I am planning to circle back and follow up soon with our New York Senators and Congressional Legislators.

Join me in this boots on the ground contact that can change our legislators' outlook. Join me in being the force locally with your own NY representatives and think about making that trip to DC to connect with your US representatives. Meeting our Loved Ones in need can make a deep impact on our legislators! We each can be part of a change and help step policies forward!

NYADD – Spotlight on a Regional Lead

By Steve Gonyea, Regional Lead (region 2)

Talk about a monumental trip! My family created a special time to remember! My wife, Jen, and I and my daughter Brandi and our family friend RN Nurse Tricia McCluskey, took four teens to Washington DC for me to speak up and speak out at the National Council on Severe Autism conference and at the DC Capitol for part of an amazing week recently

To most, it would seem impossible to travel that distance and to successfully handle the situation with special needs children. But when you have an important message that the children are part of, you can make the impossible happen! Two of the four



Please click on this picture to be sent to a FB clip about these advocacy efforts

NYADD – Advocating for Self-Direction Residential Services

By Katy Faivre, State Lead

Advocacy often starts with personal experiences and expands as we connect with others who face similar challenges. NYADD members have united to emphasize the urgent need for systemic change in Self-Direction Residential services.

My journey began four years ago when my brother suffered a serious fall. His orthopedist recommended “daily” exercise beyond physical therapy, but Direct Support Professionals (DSPs) couldn’t fulfill that task. I thought pursuing Self-Direction Residential services, which could cover gym membership and a personal trainer, was a sensible solution. Like many, I initially struggled with the complex process. My Care Manager advised against it, due to insufficient budgets for group home residents, which turned out to be sound advice that I followed for a couple years. However, last summer, when my brother asked, “When can I retire from the day program?” I knew I had to re-engage. Going through the initial process went smoothly this time!

Unfortunately, nine months later, we’re still facing a significant hurdle: our Care Manager was correct – the budgets are simply too small. Determined to understand, I reached out to other NYADD families and found that Paul and I are not alone in this situation. At a recent Mental Hygiene hearing, testimony was presented of an individual’s frustration about being unable to retire due to Self-direction Residential budget constraints. Speaking to NYADD members, families reported that their Loved Ones

needed 1:1 support at home (because they could not get admitted to day programs), yet had budgets that fell short. Some parents have taken on staff roles themselves to secure necessary support for their loved ones, while others have used personal funds to cover “supplemental” costs for Community Habilitation (Com Hab) and other essential services that should be budgeted.

Alarming, many families are unaware that these services are even an option. OPWDD’s Self-Direction services offer a hopeful, person-centered approach for individuals with developmental disabilities. By utilizing personal budgets, they gain control over their supports and services, including choices about staffing, housing, and daily activities. While ongoing discussions highlight the services complexity, it is generally seen as effective for many outside certified residential settings. **However, this is simply not the case for those in certified residential settings.**

I have been actively engaging with my brother’s Circle of Support and OPWDD leadership to find solutions. Recently, OPWDD was able to share where the snag is coming from – its actually embedded in the HCBS Waiver. What can be done about this? It seems that everyone was aware that this is a problem. NYADD Regional Leads will continue to advocate to find a solution.

At 71 years old, Paul is eagerly awaiting his retirement, and we owe it to him - and others like him - to make that dream a reality!



Paul and his niece.

Would you like to be part of the Regional Leads’ team and help shape the future for our Loved Ones? We are always looking for family members to join us in the effort to stand up and be counted as a voice. Please email NYADDStrong@gmail.com for information