NYADD-VOCATE

Families Matter: Speaking Out For Loved Ones With Developmental Disabilities

NYADD FOCUS – Open Invitation to NYADD Families with Children in Certified Residence (Group Homes)

On November 18th at 7pm, Katy Fairve, NYADD's State Lead, and other Regional Leads will host a "Zoom information session" for families with Loved Ones living in certified group homes to share the outcomes and recommendations from several meetings with the JC and OPWDD. The Justice Center/QA Task Force (group) meetings were led by Dee Levy, Director of Prevention and Quality Improvement, and Megan O' Connor, Deputy Commissioner Incident Management Unit, OPWDD Quality Assurance and **Rita Jones-Safian** (region 5) for NYADD. These meetings provided important conversation that led to some changes to the process of how concerning situations involving our Loved Ones are communicated to family members.

NYADD's hope for the upcoming "zoom information session" is that many families will sign up to participate, ask questions and create connections with other families facing these same challenges and concerns. Katy's goal is to provide opportunities for families to get information that can be frustratingly elusive. As a former special education teacher, Katy is always looking to help parents acquire information that can assist their journey with their Loved One.

Please sign up for this event at NYADDstrong@gmail.com. State your interest in attending this information session. The Regional Lead team is hopeful that this zoom event is the first of several informative sessions that will help you navigate some of the complexities of the world of certified group homes.

The NYADD portion of the Justice Center/QA Task Force was led by **Rita Jones-Safian** (region 5) along with support and input from **Katy Faivre** (State Lead), **Ellen Deutsch Allexander** (Region 5), **Susan Havko** (Region 3), and **Suz Pgda** (Region 3).

NYADD – Mom and Daughter Advocate Duo!

Rose Lisi and Valoree Lisi

Rose: From the moment I found out I was carrying Valoree, I knew my life was going to be different. At five months, during a routine visit, the doctors told me that my baby had Down Syndrome. They suggested termination, telling me that it would be the best decision, but I couldn't accept that. I didn't see it as "why me?" I saw it as "OK, it's me, and I will do what I need to for her."

I chose not to undergo amniocentesis or any other tests. I didn't need to know any more than I already did - I knew I could give her a good life. The doctors were frustrated with my decision, but I wasn't going to let their opinions sway me.

When it was time for Valoree to be born, I didn't expect the struggle I would face. There were moments I was left alone in the hospital room, unable to find the doctor or even my baby. As I walked the halls determined to find her, I crossed paths with the doctor who had delivered her. His tone was cold, almost disappointed. I rushed past him, and that's when I found Valoree - tiny, fragile, and in an incubator. That moment changed everything. It was the moment I knew I had to be her voice, to stand up for her no matter what.

From that point forward, I became her advocate, her protector, and her voice in a world that often didn't understand. Every step of her life, I fought for her, made sure she had the care and love she deserved, and ensured no one overlooked her potential.

Advocating for Valoree was truly a team effort. We worked together to understand her needs and ensure she received the right support to reach her full capacity. After advocating for Valoree, I realized how that experience grew into advocacy for others. Through this journey, I began providing information, training, and support to other parents, empowering them to make informed decisions. I became knowledgeable in New York State and Federal education laws and stayed current on community issues, legal updates, and best practices in education.

I manage a caseload, attend meetings, offer telephone advocacy to parents, and help educate them to become confident parent advocates. But through all of the ups and downs of her life, Valoree's successes in so many areas have been our family's greatest dream come true.

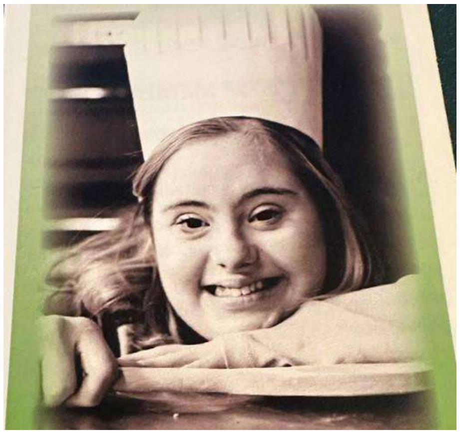
Valoree: I am a 34 year old young woman with Down Syndrome. All of my life I have known that my Mother and my family were fighting for the best for me!

During my school years, I felt that I was not very well liked by my classmates, which is difficult for anyone to feel that way. Fortunately, I was well liked by my teachers who built me up to be a well rounded student. I actually love to learn new things. I was able to be included in activities and classes like chorus and talent shows; all things that shaped me into the person I am today. Along the way, I did make some friends who saw me for me, because I am unique in my own way.

I have had and still have several jobs where I have been able to contribute greatly. When I was 14, I had my working papers ready and I started my first job with the Hudson Valley SPCA. I absolutely love this job as I love my bosses and coworkers. I have been working there for 22 years now! Everyone there knows how to work as a team. Everyone gives great advice to others and to our customers. It was a wonderful position to start my working career.

When I was just 17 years old, I started working for Price Chopper Grocery Store. I began on Siblings Week. During my first day there, a woman claimed that I smashed her loaf of bread! This was not the start I had in mind! I was able to get through that situation and have been able to work effectively for Price Chopper. At this job, I developed two lovely friends who helped me to be the best worker that I could be there. One of my trainers was my boss and her assistant who gave me valuable support. I have worked at Price Chopper successfully for 19 years.

When I was 23, I started to work an additional position for the Newburgh Enlarged Schol District as a Cafeteria Food Prep Worker. I worked my way up to be a capable worker able to tackle multiple positions. At first, I was nervous around my bosses as I was thinking to myself: "Do they support me?" and "Where do I fit in?" As time went by, I saw that I was able to help everyone in the cafeteria, from feeding young kids to middle school kids their breakfast and lunches. I have been there for 6 years.



Lastly, 3 years ago I started a job as the Historian for the American Legion Post 1796. This job is so much fun because we get to attend various events. I take pictures and report everything on Facebook. From there I save the pictures and move them into my scrapbooks. I <u>Absolutely, Absolutely</u> love going to the meetings and their Legion Specials, especially Karaoke Nights! I will do anything for everyone at the Legion because this is where I belong as a full pledged member/Historian. It was always my dream job to become a Historian and now I have that opportunity! Everyone supports me in what I do, which makes me feel so incredibly happy.

For the future I do have some goals. I do need to be quiet, because I have to admit that I am a big mouth. I also have to learn to be positive to others on Facebook, even though they don't understand me. I have high anxiety and stress levels because of it. I have to learn to sit back and observe other's behaviors. There is a divided line between a friend and their character. I don't have to like their character because they lost their Common Sense that went out the window.

As you can see, I love to work and I love helping a lot of people in our community. I always look forward to work every morning and every afternoon. I like to see 2)2integrity and being on time (punctuality) for work. That gives peace on Earth, like being a part of something bigger. Like achieving your dreams and shooting for the stars.

My message for those with a family member with Down Syndrome: our vision is to have a way to open doors as early as possible and to give support where it is needed. We want to help to carry out your Loved One's dreams and expectations of a way to the world of being included and to promote acceptance for all individuals

NYADD – NYADD 2026 Legislative Priorities

By Shannon LaVigne, Regional Lead and Legislative Lead (Region 5)

There are several bills this upcoming legislative session that address issues of importance for families with a Loved One with an IDD. Our goal is to familiarize you with these important bills and encourage you to participate, if possible, to ensure that our families are heard and that these bills are passed. If you need guidance on how to support these bills, feel free to post your question on the NYADD page or to reach out directly to Shannon.

1)**The SEPAC bill (S7826/A8633)** requires every school district in New York State to establish Special Education Parent Advisory Councils. These councils create a formal partnership between families and school districts to improve outcomes for students with disabilities. The councils ensure that families and the dedicated special education staff who support them have a seat at the table in decision-making. They provide training, resources, and a platform for collaboration. Many states, including Massachusetts, have long required SEPACs, and this bill is modeled after those successful systems. NYADD supports this legislation because it ensures transparency, improves communication, and elevates the voices of those most directly impacted by special education policies.

2)**The Blue Ribbon Commission bill (A6021/S4841)** creates a statewide commission to evaluate the future of New York's services and delivery systems for individuals with intellectual and developmental disabilities. NYADD supports this bill and successfully advocated for the inclusion of self-advocates and family caregivers, including those representing individuals who cannot speak for themselves, to ensure meaningful representation in planning and reform efforts.

3)**The Ombudsman bill (S4871/A7465)** would strengthen oversight and accountability within disability services. NYADD is advocating for this bill to include a yearly public report, a practice already in place in states such as New Jersey, to ensure transparency and measurable outcomes that support individuals and families.

4) Another important issue is the safety of Loved Ones with IDD who need to enter a nursing home or an assisted Living facility. NYADD strongly supports Assemblywoman Amy Paulin's **bill A1967 to Protect Individuals with Developmental Disabilities in Long-Term Care**. The bill would allow electronic monitoring in assisted living and nursing home facilities. This bill (A1967) allows residents or the

families to install electronic monitoring devices in bedroom area.

Many individuals with intellectual and developmental disabilities transition into these settings as their medical needs become more complex and can no longer be managed in community placements or at home. These individuals are uniquely vulnerable, often unable to communicate when neglect or mistreatment occurs, leaving families desperate for safeguards that ensure their loved ones receive appropriate and respectful care. This legislation provides peace of mind and protection for vulnerable individuals and their families by ensuring safety and accountability in care environments.

Currently, only common areas in these facilities allow cameras, but that offers limited protection. Assemblywoman Paulin’s bill acknowledges the reality that cameras in personal rooms would help deter abuse, increase accountability, and give families peace of mind. Eleven other states have already adopted similar policies either through legislation or Department of Health protocols, demonstrating that electronic monitoring can be implemented responsibly and ethically while preserving residents’ dignity and safety.

NYADD State Lead Katy Faivre has personal firsthand experience navigating these concerns while supporting a Loved One with developmental disabilities living in a long-term care setting. Recovering from a fall, her brother was in a local rehabilitation facility for several weeks. “Its his room and it should be his choice. I worry every minute that I’m not there because he cannot communicate his needs effectively. It’s happened - they don’t cut up his food, or realize that he has Cerebral Palsy when they get him up. I am unable to be present around the clock. There is a significant gap in his safety and support. Its really helping him and the staff.”

Implementing video monitoring is a critical measure to ensure staff accountability, provide immediate oversight and offer him the social connection and protection he urgently needs. Staff in assisted living and nursing homes are primarily trained to care for elderly residents and are often unfamiliar with the unique medical and behavioral needs of individuals with IDD. Allowing electronic monitoring is a practical next step that will protect a vulnerable population and provide essential transparency, ensuring that every person, regardless of disability, receives safe, compassionate, and high-quality care.

NYADD – A Self Advocate

By Dustin Gonyea

A few months ago, Dustin was asked to participate in the 35th anniversary of the Americans with Disabilities (ADA). For the first time in his life, Dustin wrote a speech and spoke in front of a gathering. Here is his speech from that day.

Look out! Here comes Dustin Gonyea, a new self advocate!

Good morning. My name is Dustin Gonyea and I am here today to speak on behalf of myself and many of my friends with disabilities.

I started at my program in 2011. It’s the Venture program through the ARC. My program has helped me grow in many different ways.

In 2011, I was very shy and would have never spoken in front of others. I became more independent with my program and my staff really pushed for me to do as much as I could for myself. I started going out in the community on many different volunteer sites.

I volunteer at different firehouses, libraries, grocery stores, the ice cream shop and Hamilton College where I do many different tasks.

Then there are the fun outings where I am out communicating with the public. I have made many new friends and have had a few jobs because of inclusion.

I would never say NO to anything before, but I have learned that it is okay to NO and be an advocate for myself.

Click on the picture of Justin to watch his speech

NYADD – The Journey towards Handing over the Reins of Advocacy

By Steve Gonyea, NYADD State Lead

My autistic son with disabilities, Dustin, is 35 years old. How appropriate that on the 35th anniversary of the Americans with Disabilities (ADA) he self advocated for the first time. Ever. He has never talked in front of crowd.

My son didn't talk for many years. When he did talk, it was a few words here or there. Or just a yes or no answer. I have advocated for him for years. But on this day, he advocated for himself.

I couldn't be prouder. If I never spend another minute advocating for him and others, this will be the moment that I remember most. I was so proud of him.

Not only did he move his own needle, but others did too. Those that helped him along the way. The supports around him that helped him along the way. Everyone and everything he did helped him to move the needle.

I didn't write his speech. I didn't write the words. I didn't even help him with it. He wrote it and I couldn't have made it better if I had tried. And I talk to people all the time. The program he attends let him practice with them. When I asked him before he went to the podium if he wanted me to stand with him, he said – "No Dad. I have this. I will be okay". He was more than ok! It was one of those moments in time that we as disability families call priceless!

Without OPWDD and his support systems helping him and supporting him along the way, none of this would have happened. Thank you for giving his Dad and Dustin this memory and this moment.

Steve and Dustin Gonyea

NYADD – The Ability Bus - Utica in the Forefront of Change

By Steve Gonyea, NYADD State Lead

The cavalry is not coming, so the cavalry has to be us!

This is an often repeated phrase by Steve Gonyea. Steve challenges each of us to step up and find where we can create a difference for the good of the IDD community.

People around the country are starting to take notice of the remarkable solutions for people with developmental disabilities that are happening in Utica, NY. Emmy-award winning documentary filmmaker, Michael Skinner, and his DC-based company, Pendragwn Productions, have visited multiple times to amplify the solutions Steve Gonyea and his family have created for their children with autism. In fact, Skinner and Gonyea are collaborating to form a new nonprofit called WorthDoing.org.

The organization is creating a website featuring documentary films and action toolkits to help spread simple ideas that work for other communities around the country. The first toolkit will feature what they are calling the Ability Bus. They are using the model Gonyea and Utica Center for Development founder, Vin Scalise, created: purchasing a small, used school bus with a wheelchair lift and organizing volunteer drivers to provide free transportation to families and organizations who are facing any kind of challenge.

Solving the transportation crisis for people with disabilities allows them to focus on their abilities, not their challenge;: hence the name Ability Bus. WorthDoing.org will feature a short documentary about the Ability Bus, a how-to video, and an FAQ on their website.

Gonyea and Skinner have set a goal of inspiring 100 other communities to adopt the Ability Bus model in 2026. Ideally the goal would be for at least one bus in every state plus the District of Columbia. Gonyea and Skinner plan to create additional toolkits for other ideas that are worth doing. They believe that individuals and community groups have the power to solve many of the issues around us and just need a good plan to get things done.

WorthDoing.org will create a community of change-makers across the country. Gonyea is already fielding calls and emails from people around the country who are interested in learning more about what is happening in Utica, NY

The Utica Ability Bus

NYADD – Autismo Café: Brewing Inclusion, One Cup at a Time

By Jillian Eisloeffel, Regional Lead (region 3)

When Miguel Nolasco's autistic son faced judgment in everyday public spaces, he imagined something better. A place where families like his could exhale, connect, and belong. That vision became Autismo Café, a warm, vibrant space that is more than just a coffee shop: it is a community haven. From the start, the café's mission has been clear: to create an environment where individuals with autism and their families feel safe, accepted, and celebrated. No sideways glances. No judgment. Just good coffee, food, meaningful connections, and a sense of home.

What began as one father's dream has blossomed into a gathering place for people from all walks of life. Families with special needs are at the heart of Autismo Café, but the community extends beyond to neighbors, educators, advocates, and even those without direct ties to disability come together to share in the café's inclusive spirit. The response has been so powerful that Autismo Café is already considering expansion to meet the growing demand. With classes in art, wellness, and yoga; workshops that promote awareness; sensory-friendly events; and celebrations tied to inclusion, mental health, and heritage months, the café offers something for everyone. The message is clear: inclusion resonates, and people are hungry for spaces where it is not only welcomed but embraced.

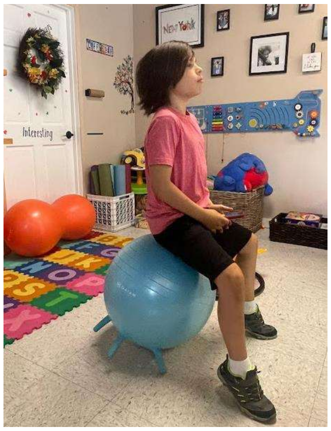
At the heart of this is Wendy Javier, a co-partner, founder of Infinite Heart Initiative and guiding force behind its mission of safety, healing, and inclusion. With a deep passion for creating spaces where people feel safe, supported and most importantly free to be themselves. Wendy bridges the café and the community. Her leadership transformed Autismo Café into more than a business, but a living, breathing movement of inclusion. Through efforts families gain access to lifesaving resources such as:

- Medical ID bracelets with QR codes which give first responders immediate access to vital information.

- Blue Envelope which supports drivers with disabilities in their interactions with law enforcement.
- Sunflower Lanyard Initiative which discreetly signals hidden disabilities and promotes understanding in public spaces.

Autismo Café stands as proof of what can happen when lived experience meets determination. What started with one father's desire to carve out a safe space for his child has become a model of community-driven inclusion and a beacon of hope for families across New York and beyond. Whether you're coming for a cup of coffee, a calming class or a workshop that builds awareness, it's a place where everyone belongs.

Autismo Café isn't just serving coffee, its serving community, compassion, and a vision of inclusion for all.



Autismo Café
690 NY-211 East
Middletown, NY 10940
845-673-5052
**Some classes/workshops are approved through self-direction.

NYADD – Spotlight on a Regional Lead

By Deidre Despaigne, Regional Lead (region 3)

My name is Deidre Despaigne and I am a proud parent to three children who are profoundly autistic and one who is also deaf. I also foster another child with autism, but with minimal needs. I was a case manager for over 10 years and now an independent support broker for 8 and I volunteer my time on various boards and committees, including NYADD as one of the Orange County Regional leads.

Why did I become a NYADD Regional lead when my schedule with my children is jam packed and I already have a long list of commitments? To be honest, I have determined that I wanted to be a ripple in the wave of change as part of the thousands of followers and advocates on the NYADD FB page. I saw pictures of fellow advocate and regional lead, **Susan Havko** (Region 3), leading a rally at Letchworth Village. Holding her protest sign high, I knew that I had to be part of the parents and advocates willing to stand up for our Loved Ones. That picture gave me the inspiration to step up and be part of the change, not just a confused and lost Mom. I didn't want to stand on the sidelines when my own children's future and other families' children rely on our advocacy.

Susan Havko leading a NYADD rally July of 2020

As a parent to one adult and two more quickly becoming adults, I can stand up and be counted and make a difference in their futures! Together we can show strength in numbers and together change the future.

Deidre Despaigne with her children who have inspired her commitment to be a force of change

NYADD – The Housing Crisis and Creating Solutions

By Doreen Jaggs, Regional Lead (region 5)

Adults with autism and other developmental disabilities face a growing housing crisis marked by limited options, inadequate support, and overwhelming uncertainty. More than 80% of adults with autism currently live with aging parents or caregivers, placing families under immense stress about the future.

As caregivers age or become unable to provide support, the absence of sustainable, inclusive housing options leaves individuals vulnerable to crisis placements, institutionalization, or homelessness. Traditional residential programs are often expensive and ill-suited to meet the unique needs of this population, leading to reduced independence, community disconnection, and diminished quality of life.

One promising solution lies in reimagining how self-directed budgets can be used to support housing. These budgets are designed to give individuals with disabilities greater control over their services and supports. By allowing a portion of these funds to contribute to nonprofit-led sustainable housing initiatives, individuals and families could help shape the environment where they live. This would allow prioritizing cultural fit, community ties, and customized support. This approach not only respects personal choice, but also encourages long-term stability through housing models rooted in community integration and continuity of care.

Furthermore, channeling self-directed funds into nonprofit housing efforts creates opportunities to scale impact. Nonprofit organizations can combine these contributions with grants, donations, and public funding to create innovative, cost-effective housing solutions that serve more people. These sustainable models reduce reliance on emergency placements and institutional care, lowering public costs while improving outcomes. Most importantly, they promote true community inclusion, ensuring that adults with developmental disabilities can live with dignity, autonomy, and meaningful connections throughout their lives.

NYADD – Invisible No More: A Mother’s Why for Speaking Out

Family caregivers are the backbone of our nation’s care system. Every day millions of parents, spouses and relatives provide complex care without training, resources and support. Most caregivers are unpaid, and feel stressed, isolated, and invisible. Caregiving is frequently overlooked as something that belongs only within the household. When in truth it is what holds our system together.

For me, this isn’t just a description, it’s my daily reality. In my home, that reality is not abstract, it looks like bite marks on my hands, sleepless nights pacing the floor, and a constant vigilance that never switches off. It means every errand, every medical appointment, every crisis intervention falls on me when trained staff aren’t there, if we are even lucky to have staff at all. Direct support workers are scarce, turnover is high, and the pay is so low that keeping good people is nearly impossible.

I became more vocal because the weight of caregiving for my son isn’t something I can carry in silence anymore. Like millions of others, I’ve felt the toll on my health, my career, and my sense of belonging.

What's often called "invisible labor" is, for us, a constant and consuming responsibility. Speaking out is my way of making sure families like mine are finally seen, heard, and valued in the conversations that shape policy and support systems.

This is why I joined NYADD. The fight for visibility, recognition, and resources for families like mine cannot wait. When caregiving is treated as invisible labor, families are left to shoulder impossible burdens alone. When policymakers see our work as private family matters instead of public priorities, they dismiss the crisis that millions of households face every single day.

NYADD is here to say, ENOUGH! It is time for a national reckoning in how we value care in this country. That means Congress, states, and employers must act with policies that reflect the essential role of caregivers. From paid family caregiving programs to stronger support systems for people with developmental disabilities.

I share my "why" because caregiving is not invisible labor. It is the foundation that holds lives, families, and communities together. Until our nation recognizes that, I will not stop speaking out.

Now we need you. If you are a family caregiver, an ally, or someone who believes in dignity for people with developmental disabilities, join us at NYADD. Share your story, add your voice, and stand with us in demanding the policies and protections that families desperately need. Together, we can make sure caregivers are invisible no longer.

Jillian and her son, Bob

NYADD – An Update on the Justice Center

By Rita Jones-Safian, Regional Lead (Region 5)

Representatives from NYADD met with representatives from OPWDD and the Justice Center on 8-27-25 (after several previous meetings). NYADD made the following recommendations which OPWDD agrees are positive steps to take to address family concerns raised regarding incident management:

1. OPWDD will send a reminder to Providers and Care Coordination Organizations (CCOs) to reinforce the Incident Reporting required notifications for Care Managers. [Part 624 (h)(1)].
Target date: 9/20/25
Note- OPWDD issued this communication to all providers and CCOs on 9/9/25.

2- OPWDD will send out a correspondence which informs agencies that families may provide an annual written request for copies of the Form OPWDD 147 Reporting Form: Reportable Incidents and Notable Occurrences and also for items released under Jonathan's Law for investigations instead of an individual incident request for each.
Also in this communication, OPWDD will clarify that corrective action plans are part of the record and should be included in the information released.
Target date: 10/20/25

3. A checklist will be developed for people receiving services and families so they can understand and follow the steps of the incident management process. OPWDD is working on this resource in conjunction with the Justice Center and the Statewide Committee on Incident Review.
Target date- 11/20/25

Katy Fairve, State Lead for NYADD states, "The current steps are in the right direction toward helping family members of loved ones with IDD, especially those living in OPWDD certified settings. These measures are crucial to better protect individuals who are nonverbal and cannot advocate for themselves. However, the work cannot stop here - there is still much more to be done to ensure the safety and dignity of our most vulnerable."

NYADD – A Drive is NOT an Outing

By Crystal Vossler, State Lead

Imagine not being able to say what you want or need. You used to be able to go into a store with your DSP and take walks on Main Street. There's a toy in the window that you want. You see it every time you drive by. But that's all you do now, drive by. You don't understand why you can't stop; you don't know why you can't go for a walk. You scream out and you cry and they act like you're unreasonable. You can't tell them that all you want is that toy or that ice cream cone or to listen to that music in the park. You can't tell them all that you want to do is go for a walk. They just keep driving by the places you would like to visit and investigate each week. You used to be able to walk with them and show the staff things that you were interested in. Why can't they just stop the van? Why can't you just get out and show them again? The only time you get out is to see the doctor and you are afraid of him.

Even prisoners are allowed 1 hour a day in the yard. Why can't our children and adult children with disabilities be allowed the same courtesy? Our Loved Ones deserve to be part of their community and walk the same streets that we do.

For many group houses, staff are able to count going for a van ride as an outing. That may work for some group home residents and be the perfect circumstance for them when being out in the community can be challenging. Van rides are wonderful for those residents! The staff are meeting those residents' needs for going out and seeing the beauty of the world - in the way that is best for them. However, it definitely isn't a one-size-fits-all solution for an outing. For other residents, it is unfair to count driving around town as an outing.

I'm not saying that every individual has to go outside if they don't want to. I'm not saying every individual has to go out into the community if they choose not to. But everyone deserves the right to multiple options and activities. This should be evaluated based on each individual's needs. It should be reviewed annually. For some, their safe place is being in a familiar vehicle and getting to view the world from a comfortable seat in a van. Perhaps having music playing or the windows down is a perfect outing for them. Or, it is possible that driving around town and getting exposure to an environment will be enough for them to be confident enough to go outside and walk on a side street or in a park on a quiet day. They too, deserve the right to be asked if they want to go out into their community.

For many individuals, a drive around town is not an outing. It should not be considered as one if it does not suit their needs. Those individuals would flourish by access to a variety of environments. They might enjoy fairs, concerts, bowling, swimming, hiking, shopping, movies or meals in restaurants. They should be given the opportunity to try to participate in activities that would expand their horizons and enrich their lives. The activities they are able to participle in should be meaningful for them. Their lives should not be limited to van rides.

Driving past that diner you've been wanting to eat in for over a year is not fair and is not an outing. It's torture.

NYADD Regional Leads On the Move: Keeping up with the Leads

Steve Gonyea (Region 2) attended the Pathways for Success IDD/Autism event in Utica, NY in September. Steve tabled for NYADD at the event, handing out our NYADD 1 pager and the last 2 NYADD newsletters

OPWDD, the Justice Center, the Department of Education all tabled alongside NYADD and about 2 dozen IDD agencies.

Additionally, Steve pioneered and hosted the first Listening Session with OPWDD Commissioner Willow Bear for Central NY, Broome and Sunmount. 12 participants shared their stories and concerns directly with the Commissioner.

Steve Gonyea, far right. Assemblyman Brian Miller next to him. Other dignitaries there include the Oneida County Sheriff Maciol in the middle.

Simcha Weinstein (Region 4) and **Katy Faivre** (Region 3) attended the Council on Developmental Disabilities' 3rd Advocacy Institute. This event brings together families and self-advocates who are new to advocacy in order to learn basic skills, identify their personal priority and then turn that into a policy change. Simcha was on the panel this year. Senator Fahy and Assemblyman Santabarbara both spoke at the event.

Assemblyman Santabarbara Chair of Pwd committee with Simcha Weinstein in the left picture.
Katy Fairve, Simcha Weinstein in the back and Shameka Andrews with SANYS in the right picture.

Dadvocating: Empowering Fathers & Male Caregivers

A new adventure for Simcha is hosting a new podcast specifically targeting and reaching Dads and caregivers of special needs children/adults who could benefit by extra connections with other Dads on the journey of parenting a child/adult with special needs. Tune in and sign up to give it a listen!

A TRAINING SERIES FOR PARENTS & CAREGIVERS

Families Together in New York State

REAL TALK

REAL TOOLS REAL SUPPORT

POSITIVE PARENTING LANGUAGE

Tools for Strength-Based Caregiving

Mon 27th Oct
10-11.30AM

Discover simple, everyday language tools that build trust, encourage growth, and empower both you and your child. Discover practical ways to cultivate calmness, clarity, and deeper connections at home and in care settings.

SCAN ME

Instructors: Simcha Weinstein & Kim Kaiser

Continuing education Credits FPA's & YPA's.
Questions? sweinstein@ftnys.org

Simcha's new podcast flyer

Peter Zummo (Region 2) the NYADD State Lead focusing on Communication, attended the recent Bi-monthly Family Stakeholders call with the Commissioner and her team. Questions were submitted by NYADD and other family group representatives.

In this past meeting, questions were asked about the change of video monitoring in residential school setting and how more family advocates can be part of the Developmental Disabilities Advisory Council.

If you have any questions or would like clarification on some issues, please reach out to Peter Zummo and he will try to get them on the agenda.

This is a zoom meeting that any family member can join. Contact Peter for further information.

Katy Faivre (Region 3), **Rita Jones-Safian** (region 5), **Russell Snaith (NYADD founder), Ellen Deutsch Allexander** (Region 5) and **Eileen Benthal** (Region 5). attended the Long Island Legislative Breakfast. They tabled the event with the NYADD newsletter and a NYADD 1 pager.

Eileen reported that her family got to meet Acting Commissioner Willow Bear and Legislative Director Greg Roberts.

Rita and Katy at the LI breakfast

Katy Faivre (Region 3), attended two meetings with the Council on Developmental Disabilities. She attended both Individuals and Families Committee and The Systems Change Committee.
She attended the Prospector Theater's Do Good Business conference for inclusive, competitive employment practices.
Katy also interviewed with her brother Paul for CDD's, training video focusing on including seniors with IDD in local senior centers.
She coached 12 athletes in the Hudson Valley Special Olympics Golf Tournament.

Katy (front left) with the golfers she coached

She is a member of the Mid Hudson ARC Board. Additionally, Katy is the OPWDD Family Stakeholder moderator, an important role filled by our NYADD State Lead.

Rita Jones-Safian (region 5) helped organize and led the Long Island Listening Session with OPWDD Commissioner Willow Bear on Oct 2nd. 14 family members shared their stories and concerns with the Commissioner. Each story was different, but equally impactful. All the family members are committed to sharing their stories loud and clear until they are heard because, "every individual deserves good health, happiness, dignity and protection." Everyone walked away from the meeting with hope.

The group who spoke to Willow Bear

Rita also led the Justice Center/QA Task Force (group) along with **Katy Faivre (State Lead), Suz Pgda** (Region 3), **Susan Havko** (Region 3) and **Ellen Deutsch Allexander** (Region 1).

Rita recently met with Assemblywoman Jodi Giglio and State Senator Murray at Sen. Murray's office to discuss funding, advocacy and oversight for those with IDD, Profound Autism & Special Needs.

Assemblywoman Jodi Giglio, Rita, and Senator Murray

Doreen Jaggs (Region 5) a new NYADD Regional Lead and Board Chairwoman of Autism Communities, is passionately committed to building inclusive neighborhoods for neurodiverse individuals.
The Friend Responder Campaign, which Doreen was instrumental in creating, launched with the Suffolk County Police Department in 2024. This program fosters trust and understanding between first responders and neurodiverse residents through.education and direct connections.

First responders

Doreen also recently participated in a panel discussion at the Inclusion Done Right Conference hosted by Stony Brook University.

Shannon LaVigne (NYADD's Regional lead and Legislative Liaison) attended The Center for Disability Services at their 29th Annual Buddy Walk to celebrate and support the incredible work of the Down Syndrome Aim High Resource Center. Shannon attended with her son, Riley, a self advocate, to connect with more families and share resources at the NYADD table.

Shannon shares, "I've said it before, but nothing makes an impact quite like putting a face to the calls and emails that we have sent out when it comes to our Senators and Assembly members. Summer is the perfect time. There are many meet and greets at farmers markets or local parks, which are much easier for our Loved Ones to go to. Riley and I headed out to a park just five minutes from our house, and in less than 20 minutes we had our assemblywoman offer to support two bills I've been trying to talk with her about."

Assemblymember Gabriella Romero with Riley

Riley with Assemblymembers Phil Steck and Janine Lampo holding a big head photo of her son, Mason