NYADD-VOCATE

Families Matter: Speaking Out For Loved Ones With Developmental Disabilities

NYADD – Why and How to Join

By Susan Brunjes, Moderator

NYADD has 3 moderators. Beverly Roach , Susan Brunjes, Renee Diflippis.
As NYADD, our focus is on advocating for our DD/ID Loved Ones and giving them the best life we possibly can. We fight for our DSPs because they are the backbone of our cause. This group was started by Russell Snaith and a group of parents who saw during Covid lockdown how “we desperately needed change”. Group homes were left out of any category. During that time as we stood up for our Loved Ones, NYADD was on news outlets statewide and showed NYS how we can fiercely advocate as a group. Our Regional Leads meet with OPWDD and legislators statewide.

Upon requesting to join the NYADD Facebook page, we ask 3 simple questions. The three of us go through all the new member requests, comments and posts before a new member becomes active. We constantly talk together with any concerns that may arise. We want to make sure you’re there to help our Loved Ones, our DSPs, and participate with other concerns. If the questions are not answered, we do decline your participation. Often, we see advertising for services and or products that do not relate to or help our Loved Ones with DD/ID. Those posts will be declined. We want to continue to keep our focus on Advocating. We need to stay NYADD strong. After all it takes village! Let’s fix this broken system together!

How to join NYADD (video)

NYADD – Regional Leads making an Impact

By Heather Ash Burroughs, Regional Lead

As a parent and a professional in the special needs community, I have noticed some “disconnects” between families and services that felt repairable prior to the pandemic. As the I/DD Crisis has unfolded, the “us versus them” mindset has grown, and so has the divide. This saddens me because we all care about this population. Even when it might not feel like it, we are on the same side, and we would be stronger if we advocated together.

When I first pitched the idea of launching a podcast, our goal was simple: “**Growing Purpose, Cultivating Inclusion**” would focus on Homesteads for Hope’s mission. We’d provide valuable content for families and professionals, and hopefully spark some much needed advocacy beyond our farm. In June, a very simple post snowballed into something special. I asked people connected to NYS group homes to share their story. That post blew up and then so did my phone. We had already highlighted some struggles families had faced and fully expected more loved ones to come forward. Some did, but overwhelmingly, it was NYS employees working in OPWDD group homes that wanted a chance to share their perspective. As I screened potential guests, I quickly learned that the crisis was much worse than I had originally thought.

Like so many of us in the special needs community, I am up at night worrying what will happen to our children when my husband and I are no longer here. I started working at Homesteads for Hope, so I could help create new options for families as I saw how the traditional systems continue to crumble.
I did not expect to feel such an immediate allegiance to the Direct Support Professionals (DSPs) who reached out. It took a few minutes and a few tears to realize that when we put titles aside, **we are all caregivers** who truly care about the I/DD population. We all feel unseen (or even abused) by the systems designed to support us. It feels good knowing that over 12,000+ people have already watched these interviews. Now it is your turn:

- ***Breaking the Silence, Part One:***
- ***Breaking the Silence, Part Two:***

Once you hear the reality of what is happening “behind closed doors,” you’ll appreciate why some of our guests chose to protect their identities. We are forever grateful that they stepped forward to “break the silence.” This problem is too big for any one group to solve on its own. It is our hope that as more people watch this series, we find more reasons to come together and advocate for a future where ALL people are treated fairly with the dignity and respect, we all deserve.

What happens behind "closed doors" (video)?

NYADD – Create a Way

By Steve Gonyea, Regional Lead

My wife and I find ourselves as the parents of an autistic adult child and the current therapeutic foster parents for seven autistic and disabled children in our home. At times, we wonder how we can manage the daily needs of 1 disabled child, let alone additional children. I can't tell you how many times, for so many years, we were frustrated and hopeless and exhausted and even angry at a broken system that did not meet the needs of our son and so many others. Our son was one who fell through the cracks in many ways, especially the recreation and social pieces that he longed for. He wanted a sense of belonging. He wanted to be able to go somewhere to meet people. Somewhere without massive restrictions and roadblocks. There were not many opportunities for adults with disabilities and autism to just go and hang out with friends, or have the opportunity to make new friends or to just be by themselves.

When we realized that no providers offered anything that fit our son's needs, we set out to build something for him on our property to hang out in suited for HIS needs. It was supposed to be a 10' x 12' shed. It turned into a two story barn. Along the way we realized that there was a need for others similar to our son - all needing somewhere cool to go to. Mind you, this was designed and built pre COVID. It wound up being a lifesaver for our son and to this day for so many others after COVID.

As word spread about the Barn, others started to come. We put things in the Barn that were sensory related, music related, hands on related, environment/mood related and autism related. We needed a sense of quiet, but also a place that allowed gathering. We installed things that had a "WOW" factor. Instead of doing what all the other agency rec groups did, with all the participants doing the same thing, we installed "out of the box" and "creative" things to do. We also included cool, old fashioned things that worked for our son and others like old record players, 8 track players, cassettes, guitars, drums, and other musical equipment, a snack bar, a popcorn machine, a beverage soda bar, sensory stations every few feet with stools that contain electronic hookups on a live edge platform shelf for Nintendo Switch, personal dvd players, iPads, laptops, etc all with their own headphones for privacy and quiet. We have 20 stations/stools visitors can sit at. We purchased sensory items, Lincoln Logs, and Legos, along with a host of build your own things (and knock them down without anyone saying anything). And you know who did the testing to see what worked for those kids and adults with disabilities? Those with disabilities!! We even push outside the barn for s'mores nights and sports.

And you know what? No one says anything, if an autistic kid picks up a guitar or a drum or wants to see how an 8 track works. Hands on…& sensory to THEIR NEEDS. A cool and creative surrounding that stimulates new senses and a new environment. And they all want to come back…after they leave.

Spectrum News did a story on us because someone tipped them off that we were doing this for **free** for those with autism and disabilities. We had been open for three years before that interview! Parents contacted Spectrum News and us to find out if they could visit, or if their group could come over. Yes to all of that!!. They also asked how to do something like this in their area.

Our point is this…we can no longer rely on agencies and providers to help our children and family members. They all have their niches and attempt to do what they can. As parents, we know it's not enough. I believe providers have lost their way in regards to including parents in their programs and activities. That is why we continue to hear about our Loved Ones having little to do. Let's show these providers and agencies the way. Let's get creative. Let's find a way. And as parents, let's bring these out of the box ideas to them. We cannot wait for them. My wife and I couldn't wait. So we did a NEW thing. We showed the need. We showed "THEM" the way.

As NYADD members, it's time for us as parents to take back the reins so to speak regarding our children. I urge all of you to do this in your own way. Reach out to us and we will be the ones encouraging you and helping you.

Respectfully, Steve and Jennifer Gonyea

Barn provides fun place for those with autism (video)

NYADD – a Mother's fears realized

By Barbara, an anonymous mother

I am a parent of a sweet, helpless and trusting 30 year old, nonverbal, special needs young woman. Deciding whether to place her in an adult residential program was one of the toughest decisions I've ever had to make. There was so much to think about and take into consideration when making such an important decision because this is where my child will live and be happy when they are not with their family. Her home away from home for (hopefully) a very long time or forever.

One night, as usual, I called in to see how my girl was doing. I was told she was fine and doing well. I told them I was glad to hear that and that I planned on bringing her home soon. Within an hour I received a phone call from a house supervisor telling me that my girl had a little bruise, but that she was okay. I was alarmed because it was not mentioned during the previous call. I asked them how it happened and to send a picture. They told me that she tripped on the second step going into the basement.

I was beyond shocked when I saw the photos and so upset! My girl was bruised from her ankle to her knee. The next photo her face looked swollen. The photo was a side view so I asked them to send a full on shot of her and I could NOT believe what I saw! She had not one but two black eyes and it looked like her nose was broken! Also, her fingers were mangled and going in different directions!!! I was beside myself and demanded they take her immediately to the emergency room. This was only the beginning of an ordeal that went on for many months.

It is one of the most traumatic things that has happened to our family. These types of injuries do not happen from tripping on a second step!!! The Justice Center investigated, but failed my girl in the end, because it was unsubstantiated after all the medical proof and blatant neglect or abuse!! Unbelievable! What a hard pill to swallow!

If there were cameras in that home, we would have had the answers my nonverbal child could not convey to me. Something needs to be done! There are cameras everywhere in our everyday lives. They are everywhere we go – stores, businesses, parking lots, sidewalks, and street corners. We need cameras in these group homes immediately to protect our vulnerable Loved Ones, nonverbal and verbal and capable. We also need them to protect the staff from false accusations.

Most programs have good intentions, but life happens. Miscommunication happens, mistakes happen, staffing issues happen, behaviors happen, neglect happens, accidents happen, abuse happens!! It all happens!! We need to do something about it!! Cameras only make sense!

Hear a Mother's Plea video

NYADD – How to handle an injury or neglect to your Loved One

By Marilyn Dagostino, Regional Lead

Many people on this FB page have been reaching out when their Loved Ones are subject to abuse or neglect. The information written below is to give you an action guideline. This will remain a living changing document that will be updated as information changes.

Abuse and neglect are very serious concerns. If a person/worker is found guilty of abuse, they will never work in the field again. Most DSPs, Res Hab specialists, Com Hab mentors and teachers do an amazing job earning very little money and give a lot of love and support to our Loved Ones. However, abuse or neglect unfortunately can occur. As difficult as this is, our most vulnerable Loved Ones need to be protected and families need a game plan.

Stay as calm as you can and work through the action steps below to find help for your Loved One.

NYADD-Reporting injury or neglect.pdf

NYADD – Ombudsman RFP

By Katy Faivre, Regional Lead, Hudson Valley and Paul's sister

What is an Ombudsman (video)?

"Ombudsman" is a Swedish term meaning "representative of the people". Originally created to be "an ear for the people", the goal of an Ombudsman is to stand up for families and their Loved Ones when there is a concern. An Ombudsman should have the authority to investigate and file complaints against organizations, agencies or officials. They seek resolutions to concerns and complaints. They often have the power to request key documents, interview individuals, and order a legal investigation, if necessary. Depending on the authority given to the Ombudsman, they may make rulings that are legally binding.

Governor Hochul's plan to provide the Office of Ombudsman for our family members is a welcomed addition to services! We all agree that an independent advocate to help with concerns for our family members is a priority, since there currently is no place to go. NYADD has shared our "priorities" for what the Ombudsman should look like with OPWDD, who has assured us that they will be reviewed for consideration when choosing the RFP (Request For Proposal). I hope that the Commissioner, who is responsible for appointing an Ombudsman, is able to review and understand what NYADD concerns are. Priorities are in the NYADD "files" for you to see. We're always available to discuss if needed!

NYADD Regional Leads met with Senator Mannion's staff recently and reviewed our priorities for this program. We thank Senator Mannion for sharing the very strong letter he sent to OPWDD as a result of this meeting, in agreement with many of our concerns. Once again, Senator Mannion has shown his understanding and support for what families and individuals need.

The RFP for the Independent Ombudsman will be announced by OPWDD soon. As family advocates, we must voice our strong reservations for the details of the law that was passed with the 2023-24 budget (a little difficult to find, but its MH Law 33.28, https://casetext.com/statute/consolidated-laws-of-new-york/chapter-mental-hygiene/title-e-general-provisions/article-33-rights-of-patients/section-3328-effective-10302023-independent-developmental-disability-ombudsman-program)

Many important details were removed from the bill that was proposed by Senator John Mannion https://www.nysenate.gov/legislation/bills/2023/S3108 . Some wording is quite confusing and unclear about key factors - what "Independent" means, provisions such as precluding organizations who provide services (or their associations) from applying and requiring that an annual report go to the governor (as with other Ombudsman in NYS- yes there are several!)

We hear every day from the many NYADD members who need help and have nowhere to turn except to each other through our FB page. We hear every day family members and self-advocates that we need this Ombudsman program. The requirement states- "180 days after becoming law"- That's October- So looking forward to seeing some results soon! I'll continue to follow this issue, so please PM me or share your thoughts with NYADD members! **#NYADD Cares! #NYADD Strong!**

NYADD – A spelling journey

By Stacy Reed Mason

My name is Stacy Mason. I am the mom of two young adult sons with non-speaking autism. I am also a Licensed Clinical Social Worker who has offered Parent Training for school districts in the Hudson Valley for almost 20 years.

In October 2021 our lives took an amazing turn when I took my sons to see a Spelling to Communicate (S2C) practitioner, Judy Chinitz, at her practice, Mouth to Hand Learning Center in Mt. Kisco, NY. You should know that there was no real evidence that my sons were particularly good candidates for S2C. I was sure that Tyler could read at a low elementary school level, but I didn't think that Trevor even knew his letters. But we decided to give S2C a try.

Immediately, on that very first day, I had a feeling that we were onto something. My sons seemed so interested and motivated to point to letters on the letterboards that Judy held up. They seemed to be interested in the age appropriate lessons that Judy was reading to them. They seemed excited to go to her home office each week despite the fact that they are afraid of dogs, and Judy's dogs were barking loudly upstairs.

We practiced every day, trying to learn together. By Jan 2022, the boys were spelling openly with Judy and then with me. Their thoughts, feelings, complaints, goals for the future, interests and fears all started to be expressed. It was an incredibly emotional time for all of us. The boys have voted in the last election, expressed where they would like to go on vacation, advocated for other non-speakers at an OPWDD Forum, and they are attending an Adult Education class at Westchester Community College this Fall. The boys still see Judy and attend a few spelling groups weekly.

I have become a strong believer in S2C and am in the process of completing the S2C Practitioner Training through the International Association for Spelling as Communication. I am currently seeing students in my home. If you have a non-speaking, unreliably speaking or minimally speaking Loved One, please consider trying S2C! It can be absolutely life changing. Please feel free to reach out to me with any questions at stacy.mason@lifeplanccony.com.

YouTube – Stacy and her sons' story

NYADD – On the Go

By Crystal Vossler, Regional Lead

My name is Crystal Vossler and I'm the mother of two children with Autism. We live in Wellsville - a small farming town in WNY. We live two hours away from Rochester and Buffalo, where we would have to travel to receive any services related to autism.

I started studying Special Education laws and services in the library and on the DOE websites in 2007. I became a volunteer Lay Advocate for Special Education in 2009. I then worked as a Parent Resource Specialist from 2015-2022, providing Special Education advocacy in schools and advising family members of children with special needs. I continue to volunteer providing Advocacy services.

I became a member of my local Family Support Council for OPWDD in 2017 and then a Statewide Rep in 2018. In 2020, I created the Family Support Services Saves Families FB page to represent our group's advocacy efforts to eliminate 20% withholds of funding from agencies providing FSS for individuals with developmental disabilities. We directed families on how to contact their local representatives, the OPWDD Commissioner, and the Governor through both email and social media. I used my role as a Statewide Council Member to point out to the Commissioner how providing more support for families at home helps prevent the need to place individuals in residential settings – saving both the family unit and OPWDD a significant amount of money. We were successful in preventing the 20% withhold for the following year and agencies received money back from OPWDD for the last quarter of 2020.

Becoming a NYADD Regional Lead seemed like a natural next step for continuing to advocate for families across NY. Advocacy is incredibly important to me and I would like to empower as many people as possible. Being a part of NYADD allows me to connect with many caregivers of children with develpomental disabilities and to be more aware of issues throughout NY.