NYADD-VOCATE

Families Matter: Speaking Out For Loved Ones With Developmental Disabilities

NYADD – Next Steps in 2024

NYADD started this year with an announcement of reorganization and transition, as founder Russell Snaith stepped into a State Lead/Advisory Role and Katy Faivre (former Hudson Valley RL) will be heading the group as State Lead. Steve Gonyea, Heather Burroughs, and Simcha Weinstein have stepped up as State Co-Leads, forming a five-member leadership team that will help to organize, plan and spearhead campaigns and communication. In his recent announcement Russell stated, “Katy has demonstrated unwavering commitment to this work and group, has vast knowledge of the system and excellent interpersonal skills. As I became pulled away by multiple demands, Katy stepped up and showed leadership by keeping people and things together and moving forward. That is leadership”.

Overarching core values, developed through Russell’s recent survey of NYADD members established Family Voice, Peer to Peer Support, Support All Caregivers, Increase Choice and Improve Quality and Safety. Katy is looking forward to continuing with Regional Leads to develop and follow through with initiatives under these headings. For example, she is following the development of the Ombudsman program which falls under Improving Quality and Safety, currently out for RFP. “Family Voice is a real priority for me and why I joined NYADD. We are working to keep the family perspective for both individual and policy concerns. I think that this has been lost over the decades. Remember, families were in the forefront of advocacy during the “Willowbrook” days. Family voices made things change. Now we are in the minority in terms of representation. I believe the reason we have 12,000+ members, daily asking for advice is because NYADD is the best way to find the answers they need- Peer to Peer!”

What do I do when? Where do I go? These are important characteristics of NYADD’s membership main page. Then we have the Regional Leads from across NYS, meeting monthly on issues both big and small. Our Regional Leads take issues that are both important to them and to the broader group and try to share advocate from “our” point of view. “Our lived experiences are very diverse, and that’s the best part about NYADD as a grassroots family advocacy group. We’ve got different perspectives, but stick together for the common goals.

Working with the State Co-Leads, Katy hopes to lead NYADD by inspiring others to take action. “It’s a vast system, and we need everyone to pitch in, follow their passions and work together to make a difference. NYADD Regional Leads are a diverse group of close to 50 family members from across all regions in NYS. Our diversity gives representation to many initiatives and needs, but what we all have in common is the need for the voice of family to be in the forefront of our advocacy.”

Katy Faivre being interviewed by Fox news following the March 8th at Letchworth Village in Thiels, NY.

The crowd at Letchworth Village in Thiels, NY.

NYADD – Why Should I Care, part 1

By Marilyn Dagostino, Regional Lead

I am a special needs teacher and a mommy of two with challenging disabilities. Because of my unique position of being a mom for 42 years and a teacher for 45+ years, I have a trail of experience that I continue to walk.

I remember of the horrors of WillowBrook and applying in the aftermath for a teacher's job only to be told at the time I was too small and too newly educated for the job. The recruiters at WillowBrook were looking for men, especially big men. Little did I know that my own child would be born with Cerebral Palsy and Developmental Delays. Two years after that, I landed a job for the Board of Education in one of the first Center for the Multiply Handicapped in New York City.

Before the Centers for the Multiply Handicapped were created**, there was little to no educational opportunities for those with disabling conditions.** I was blessed that during my masters degree placement I was in a setting for those diagnosed with dual disabilities. This usually meant an intellectual disability and a hearing or visual disability. It was on the fifth floor of a local school and there were three classrooms. It was ***considered revolutionary*** at the time. This was in the 1970s.

The Center for the Multiply Handicapped was spearheaded by the Stern family to include their son, Howie, for a school placement. He was in a wheelchair and *accessible buildings did not exist.* The school was located in a beautiful building built by the state with wide doorways and large classrooms each with its own bathroom. It is now the headquarters of Mercy College and a huge medical center.

The building, when we occupied it, was eerie. I clearly remember a nurses station at the beginning of each wing with bedrooms down the hallway. It was clearly built as a hospital setting and an institution. There was a therapeutic pool and a huge gym. As the only occupants, aside from state offices, we were able to utilize all areas for our students. One young man came in clearly very disabled and his mom arrived with him, constantly kissing him saying, "it's your first day at school." He was 17.

This is why we NEED to care. ***The beginnings of obtaining services and education for our disabled population was on the backs of parents***. Before the board of education started to create classes and schooling, most of **the services were managed and provided by parents.** I am just including one example, AHRC, but the organizations that provide the majority of services today were founded by parents. https://www.ahrcnyc.org/about/history/
This was before the internet, so we met in living rooms and community centers. We marched in Albany in huge groups spending our own time and money just to get some sort of services. **There were absolutely NO services available for most children and adults with a developmental disability. NONE! Parents were not waiting for services, there were NO services!** In addition, to our hard work as parents, further changes were brought by the passage of the Education for all Handicapped Children Act in 1975.

The first group homes were developed by the very same parents who created the current organizations. Without the hard work of **parents just like you**, there would not be group homes. One of the first group home was established around the east village area in NYC by parents. https://www.cdrnys.org/blog/advocacy/not-in-my-backyard/

Despite parents creating these opportunities for their children, accessing these services was extremely limited with many restrictions. For example, even today in NYC there is only one free standing overnight respite for those in wheelchairs. If you are ambulatory, yes, there are overnight respite options available, and weekend respite day programs. Currently, because of the staffing crisis, the Saturday program my son enjoyed for over 28 years refuses to take him because of his level of care. I was devastated to learn that after only one session, the agency decided that his needs were too high for their staffing. He is non-ambulatory and incontinent. Sadly, the emotional toll it takes on my son remains hidden from those that made that decision. He still asks for the bus. It is one of the agencies that was founded and still supported by parents.

The parents who journeyed before us have done the groundwork. Now we can take advantage of many offered services. We feel these are necessary services and not entitlements.

SO the question becomes, what will **YOU** do as a family member to strengthen what has been built by the parents before us?

This is why we HAVE to care.

NYADD – Regional Leads making an Impact

Family Caregiver Crisis and New Legislation: Complex Care Assistant

By Linda Molina, Regional Lead

"Today, I sat here for 4 hours doing temperature checks, nebulizers, vest therapy, manual chest PT listening to his lungs, late day phone calls to pulmonary and his pediatrician, deep suctioning, administering medications and bridge medications to prevent any worse seizures from occurring. It's either I do all this in the comforts of home or we spend weeks admitted to the hospital. Lennox doesn't want that. Neither do I, nor his father, or his siblings. It makes life at home hard, especially, when you can remember a time when you had so much control over your life, your finances. You could plan a trip and make plans, go to work and not worry about getting sick and missing out on holidays or events." -Lennox's Mother

With a critical nationwide *nursing shortage*, New York families, whose medically fragile children qualify for Private Duty Nursing services due to their chronic, intensive, daily medical interventions, are struggling to receive the services they need. This leaves families to consider long-term care facilities (343% higher cost than home care). Some states across the nation are adopting policies that allow for legal guardians to become paid providers, resulting in decreased avoidable hospitalizations and dependence on the welfare systems, including food and housing assistance. Dan Tsai, Director of Medicaid for CMS, said on September 5th, "*one of the silver linings of the pandemic was people seeing the impact of having paid family caregivers in the Medicaid program...we think it's important from a workforce standpoint, we think it's really important for care*".

NYADD Leads- Tara Klein, Shannon Reed-LaVigne, and Linda Molina have been working tirelessly with families across the state, state legislators, and Team Selects Home Care Agency. They would like to thank Assemblymember Phil Steck and Senator Shelley B. Mayer for introducing new legislation (A9034/S8599) that, if passed, would enact a new certified discipline within New York Medicaid. This legislation would permit legal guardians and family members of children to become paid *Complex Care Assistants* through state-mandated training, under the direction and supervision of a Registered Nurse employed by a home care agency. This would allow family members to meet not only the needs of their medically complex children, but to supplement nursing staff when unavailable, while supporting the financial needs of their families.

There is currently a letter writing campaign to support the work of complex care families. We invite you to get involved by contacting your legislators and the governor. Every call, every letter makes a difference! Tap on the link below to learn more about the letter campaign.

NYS Medically Fragile Children & their Families Need Your Help , Please Contact your Legislator in Support o...
p2a.co

Team Select Home Care

NYADD – Meet me at the Rally

Over the past few weeks, there have been several opportunities to join with other parents and families to let our voices be heard at rallies!

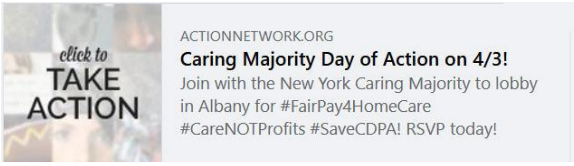
Earlier in February, there was a rally in Albany hosted by NYDA asking to support investment in the I/DD service sector.

On March 8th there were actually 2 separate rallys. The first was Rally in the Valley held at Letchworth Village in Thiels, NY. The rally was well attended with over 1200 people asking for a 3.2% COLA for DSPs and a $4000 sign on bonus. Several members of the legislature in attendanace, as well as several CEOs of various agencies.

Also on March 8th there was a rally in Long Island. This rally also had several Assemblymembers in attendance and several CEOs of agencies. The rally goers were asking Governor Hochul to meet the needs of DSPs and our Loved Ones.

These rallies were followed by CDPAP rally in Albany on March 26th. The rally theme was asking Govenor Hochul to listen to New Yorkers who need care.

This week there is a rally in Albany on Wednesday, April 3rd! Its the DAY OF ACTION RALLY. If you are interested in participating, follow the link below. We do have to be a people of ACTION and stand up for our Loved Ones!!



ACTIONNETWORK.ORG

Caring Majority Day of Action on 4/3!

Join with the New York Caring Majority to lobby in Albany for #FairPay4HomeCare #CareNOTProfits #SaveCDPA! RSVP today!

click to TAKE ACTION

NYADD – On the GO

Why I become a Regional Lead

By Chris Palega, Regional Lead and Family Caregiver

While I serve a number of roles in our community, the most important one is, of course, my role as parent and family caregiver to my 25 year-old daughter, Katherine. She's an amazing young woman who, too often, suffers with far too many challenges and who, despite all of it, possesses a level of courage that many will never know.

I've worked as a live-in DSP in a psychiatric halfway house and as a live-in residence manager for an amazing group of developmentally disabled people who remain in my thoughts to this day. I'm currently a self-employed digital sales and marketing professional working from home (or from the front seat of my car with Katherine riding shotgun). This freedom has allowed me to play a significant role in the day to day aspects of my daughter's care, and to advocate for her in the educational, medical, and legal arenas. I've achieved a lot for her and have learned a lot along the way.

About 5 years ago I was drawn to public advocacy via a Facebook post looking for volunteers to join a local FSS Advisory Council. It was the perfect opportunity to begin pursuing my desire to advocate on a scale that can be meaningful to other families whose struggles I've grown to understand. From the beginning of this journey, I've been incredibly fortunate to have inspiration and support from an amazing group of FSS Advisory Council members and others in our Community, many of whom are themselves family caregivers.

When I eventually found NYADD on Facebook, I was blown away by the knowledge and energy that emanated from the group. And being a digital marketer, I was intrigued by the possibility of contributing on a platform with the unparalleled reach of NYADD. As I began commenting, and then posting about FSS, it quickly became clear that NYADD is an environment that values knowledge, commitment, creativity, and leadership. This group has presented me with a rare opportunity to lead in the FSS space while relying on the knowledge and support of some of the most impressive leaders I've found anywhere! So why do I want to be a lead at NYADD? That's easy. I just wouldn't want to do this anywhere else!

NYADD – Taking a Stand

The Ugly Truths About the Proposed Cuts to CDPAP

By, Heather M. Burroughs of Hilton, NY
Dedicated Mom of Four Children with Disabilities
Director of Advocacy & Education at AutismUp

Governor Hochul's proposed cuts to the Consumer-Directed Personal Assistance Program (CDPAP) have placed the disability community in a precarious position. While the one-house budgets provided some protection, the finalized budget remains uncertain. Our advocacy efforts must continue to ensure policymakers understand the harm these cuts will cause and are compelled to do the right thing.

Protecting CDPAP is a human rights issue. These cuts will not only hurt some of our fellow New Yorkers, but they also reflect a dangerous mindset. We cannot let our fears of retaliation keep us silent. It is time to speak up and share what is going on in our homes behind closed doors. Most people are blissfully unaware of the challenges we are facing, how grim our reality has become. **This is a defining moment, and we must rise to meet it.**

The proposed cuts target those who need help directing their care, specifically those with Designated Representatives. It is concerning to see New York State, once a leader in disability rights, now considering using a person's disability as a reason to deny them a free and reasonable accommodation. This change would immediately impact 100,000 people who rely on CDPAP to remain in their homes and out of institutions. Ignoring ADA Law and the Olmstead Act in this manner is disheartening and feels like a step backward. My family experienced similar discrimination when my daughter's school district argued she was "too disabled" to warrant an accommodation. It took eight years in federal court to establish a legal precedent that protects individuals in similar situations. We must remind our Governor that accommodations are provided because of a person's disability, not denied because of it.

CDPAP is not just a resource; it is a cost-effective program. It helps families function and carry on with dignity when a loved one needs caregiver support. Having a choice over who comes into our home and being able to train our caregivers has been our saving grace. It keeps our dignity intact because it gives us the agency to make important life decisions.

Our greatest accomplishments in the disability community didn't start in a boardroom. They started with people sitting around the dinner table, meeting up in coffee shops, or coming to rallies like the ones taking place across our state. Invested families have the most to lose, and we are tired. If we do not fight for CDPAP, we risk losing more than just a program.

We stand at the edge of a cliff, teetering on a dangerous slope. It is time to remind our leaders that "We the People" includes us. The budget cannot help other segments of the population at our expense. Especially when no other viable alternative has been offered. If we truly embrace welcoming the huddled masses and valuing diversity and equity, then every individual, regardless of IQ or disabling condition, deserves our consideration and respect.

My family's story is just one example. CDPAP made all the difference for my father, who battled Parkinson's and dementia, and still does for my daughter, with a rare genetic disorder. But it's not just my family; it's my colleagues who remain employed because of CDPAP. It's the countless individuals I've worked with who would be stuck in hospitals or nursing homes without the caregivers provided through CDPAP.

If CDPAP is cut, my family would be drastically affected**. It is not that CDPAP makes our lives easy, but it does make it less hard.** Like many others, we couldn't secure nursing care, and we only have 30 hours of self-direction staff who are not permitted to give my daughter her life-saving medication. That leaves another 138 other hours to cover every week. If these cuts are approved, how would we sleep, let alone work or care for our other three children with varying levels of disability? We will burn out, be unable to pay our bills, and need more expensive forms of government assistance. Even the most dedicated families cannot be expected to absorb this indefinitely. With no residential options open, **what will happen to us?**

Our voices matter and our actions count. Talk to your legislators and appeal to them. Remind them that the non-speaking deserve to be heard. While I sincerely hope you or a loved one never needs CDPAP, determined advocacy will be the only way to ensure it is still there and able to help in your time of need.

NYADD – A Parent's Perspective

By Gerri Pierri, parent

We, as parents of an adult 30 year old in the OPWDD system for 25 years, are very disappointed in many changes throughout the years. To our eyes, we feel like we are seeing a decline in necessary supports. We see a lack of wages, training, and quality employees working with our Loved Ones with disabilities.

The quality of care and concern from staff in the group home setting is extremely concerning. Our children deserve high quality care. There are many times our son comes home unshaved for many days with dirty hair and body odor. How does our son feel about himself when he looks this way? Does he attend doctor appointments and go out into the community looking so unkempt? As parents, this causes a lot of stress.

The DSP employees need better wages and they need better training across all areas. The DSP workers are exhausted from trying to cover double shifts without enough employees to do the job properly. Is it going to take a tragic accident of an exhausted DSP worker giving the wrong dose or forgetting to give medicine crucial to our children to draw attention to this ongoing situation?

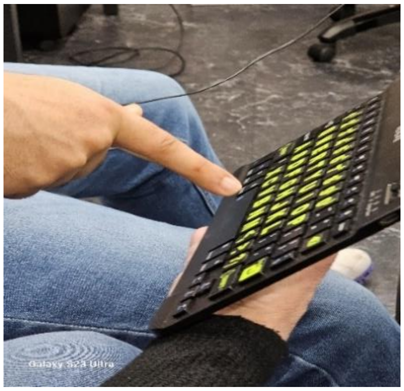
Communication is also a big problem, especially between shift changes. A clear plan for better communication in all areas is needed, including communication with parents. We have been left out of important medical conversations because we were not told about appointments. We have not been told where our son is during the day and what he is doing, or not doing. Additionally, our feedback to staff and nurses has often gone unheeded. We are currently in a medical situation that we saw the signs of months ago and we voiced our concerns. Unfortunately, there was no staff follow-up.

We know that we are not the only parents facing these realities. We think NYADD is doing a great job in supporting families with similar concerns. Its good to know that a question can be asked and answers and help given! NYADD is only a click away!

We suggest that a weekend rally would potentially draw more families and have a bigger impact to voice our concerns to our government and agencies. Let's sound the alarm together!

NYADD – A Spelling Journey

An Interview with Tyler Mason



Tyler types.
(video link)

Tyler, thank you for letting me interview you. Can you tell me how you became a speller?
Totally I am totally happy to talk about myself. Each time i am asked that question, I am going to say that i smile because it's such a happy story. Totally I first started spelling about 2 1/2 years ago. Totally i had no way of communicating before that. That was when i was 21 years old.

Were you aware of spelling as a method to communicate before you started to spell?
Totally not i had no idea that spelling to communicate was in existence.

What did spelling change about your life?
When i started to be able to spell, everything changed. Totally i am going to say that i was able to express all my thoughts and feelings. Was able to express where i wanted to go on vacation, and that i wanted to be a registered voter and vote in the next election.

Where did you want to go on vacation?
Totally to Barcelona. Totally so we went.

I understand that you are a Nonspeaking Coordinator for the Spellers and Allies Advocacy Network. What does this position entail?
That's a good question. That's tricky to answer. As the non speaking coordinator for spellers and allies I help to organize meetings, to help with social

media campaigns and help with looking for opportunities for presentations for the group with a variety totally of different people. The mission of the group is to make people aware of spelling to communicate. The two campaigns are a bipoc (inserted by interviewer for clarity - Black, Indigenous, People of Color) campaign and a campaign to educate medical providers about spelling.

How many hours of work do you do for your position?
Totally 10 hours a month.

Is your position a local job or something you are able to do online?
That's right its all online. Totally i have never had a job before and i am still shocked that i have one now. I believed that as a nonspeaker i would be without a job for my entire life.

What has spelling changed about your life?
Totally it is helping me to have friends and to communicate with my family.

Can you tell me a fun fact about yourself?
Totally i am into astronomy.

Do you prefer to use certain spelling boards?
Totally i like the laminate boards. Totally i like typing a lot but it can be more difficult.

Is there anything that you would change about your life?
Totally totally I wish that I could have started spelling sooner. Thats the only thing that I would change.

NYADD – Create a Way

What happens when dedicated parents create an event to gather everyone together to make a difference in the lives of our Loved Ones with disabilities? GOOD THINGS happen!

When was the last event that you attended where all of the parties that our Loved Ones with disabilities need to access were together in the same place to learn together? It's a unique opportunity to educate and advocate on the same day!

Better Together, a Listen and Learn event in Utica, NY on Saturday, April 6th will be jam packed with Family Advocates, Legislators, knowledgeable presenters, and practical information. NYADD is just one of many organizations hosting an informational table.

The two part event will have important information for parents, caretakers, medical providers, first responders, and law enforcement agencies, in addition to many representatives from OPWDD. The opportunity to meet and share your family's perspective is unparalleled.

Two NYADD regional leads, Kathy Caruso and Steve Gonyea helped spearhead the event. Their hard work is paying off to benefit the entire disability community. Steve Gonyea is also one of the featured speakers. Gonyea is a dedicated parent driven by a deep commitment to family and advocacy. He serves as a therapeutic foster parent, a respite parent, and an educational advocate. Steve also created **The Barn**, a therapeutic and engaging setting for those with disabilities to spend time involved with many opportunities lacking in other settings. Steve actively encourages parents to stop waiting for agencies and providers to do what we as parents can do even better.

better TOGETHER

Kelberman
The center of excellence for autism

FREE Autism Awareness
Listening/Learning Event & Training

Saturday, April 6th, 2024 | 10:00am to 2:30pm
Redeemer Church 931 Herkimer Rd. Utica, NY 13502

Better Together, a local parent support and advocacy group and Kelberman, a leading provider in Autism supports and services in central New York are teaming up to provide this full day, two-part event to the community.

Registrants may sign up for either part, or both!

PART ONE: Individuals, parents, caregivers and provider agencies come together to talk about the importance of making and changing policies that impact people with Autism and other intellectual and developmental disabilities and their families. We are inviting all New York State elected officials to attend and take an active role in listening to these conversations and to take action!

REFRESHMENTS WILL BE PROVIDED DURING THE BREAK!

PART TWO: The focus is to provide specialized training conducted by First Responders and professionals within the Human Services community to equip the community with initiatives and techniques that yield successful outcomes with interactions involving those with Autism and intellectual and developmental disabilities.

We welcome and encourage participation by parents, first responders, law enforcement agencies, provider agencies and organizations, medical providers, care coordination organizations and anyone who is an active part of the lives of those within the IDD community.

REGISTER at https://forms.office.com/r/HekM12MvqP
or by contacting Bethany Wendt, Director of Community Relations, at Bethany.Wendt@kelbermancenter.org.

For More Information Please Contact:
Kathy J. Caruso, Lead Facilitator Better Together
at kathyjocaruso@gmail.com

NYADD – FSS in Focus

Vol. 1 – Historical Context

By Chris Palega, Regional Lead and Family Caregiver

The Family Support Services (FSS) program is rooted in a demonstration project, started in 1984, to assist 200 families who were supporting developmentally disabled loved ones at home. It was established legislatively by Mental Hygiene Law § 41.43, and is supported legislatively in Chapter 552 of the Laws of 1992.

These statutes stand as powerful statements, by the People of the State of New York, on the challenges our families face every day, the stability the work of unpaid family caregivers creates for the system of care our entire community relies on, and our belief in the need for, and cost effectiveness of, a program to support families caring for loved ones at home.

Unfortunately, OPWDD administrative policies related to FSS's most popular program, Family Reimbursement, implemented in July 2022 via Administrative Directive Memorandum (ADM #2022-02R), have undermined our ability to support families via FSS Family Reimbursement. This is causing families across New York State to suffer needlessly.

Commissioner Neifeld and her team have described this ADM as a policy that is open for refinement and change. However, despite policies that appear to me to be misaligned with the legislative intent for the program, and despite the overwhelmingly negative feedback from our stakeholder community, no meaningful change has occurred. Families are giving up on obtaining critical goods and services, including much needed respite, and family reimbursement programs across New York State have closed under the additional administrative burdens of this ADM.

Among other things, Section 1 of Chapter 552 of the Laws of 1992 requires that *"family support services should be family - driven, designed to meet the needs of the particular family requesting assistance as well as the needs of the individual with developmental disabilities, and flexible enough to meet the changing needs of such families and individuals*;" Despite this, there was barely an illusion that families were engaged to drive the development of ADM #2022-02R.

Mental Hygiene Law § 41.43 (c) states that *"…family supports are goods, services, and subsidies, determined by the family and the commissioner of the office for people with developmental disabilities,…"* Despite this, what has been an ever-growing list of items and services that are not allowable was issued without families determining anything.

Mental Hygiene Law § 41.43 (c) also defines specific goals for FSS, and ADM #2022-02R recognizes these as its goals as well. Unfortunately, data and stakeholder engagement presented to OPWDD in March 2023 in the Statewide FSS Committee's report on the ADM demonstrated that the policies reduced OPWDD's ability to meet each of the legislative goals; and each of the other goals studied. The research also found that this ability had, in most cases, continued to decrease over time. ***Nothing changed.***

Senator John W. Mannion, Chair of the Senate Committee on Disabilities, and Assembly Member Rebecca A. Seawright, Chair of the Assembly People With Disabilities Committee have both sent letters to Commissioner Neifeld stating their unequivocal opposition to ADM #2022-02R. Nothing changed.

And as I said, feedback from across the stakeholder spectrum has been overwhelmingly, if not unilaterally, clear and consistent in deriding these administrative policy changes. ***Yet, nothing has changed.***

So what's it going to take to reverse a set of policies that are failing the families they should be designed to support? I think it's possible…