

NYADD-VOCATE

Families Matter: Speaking Out For Loved Ones With Developmental Disabilities

MEETINGS

NYADD regional leads connect with legislators and advisors across New York State. A few channel, or committee meetings within NYADD are included. From June 2022 to Jan. 2023:

JUNE

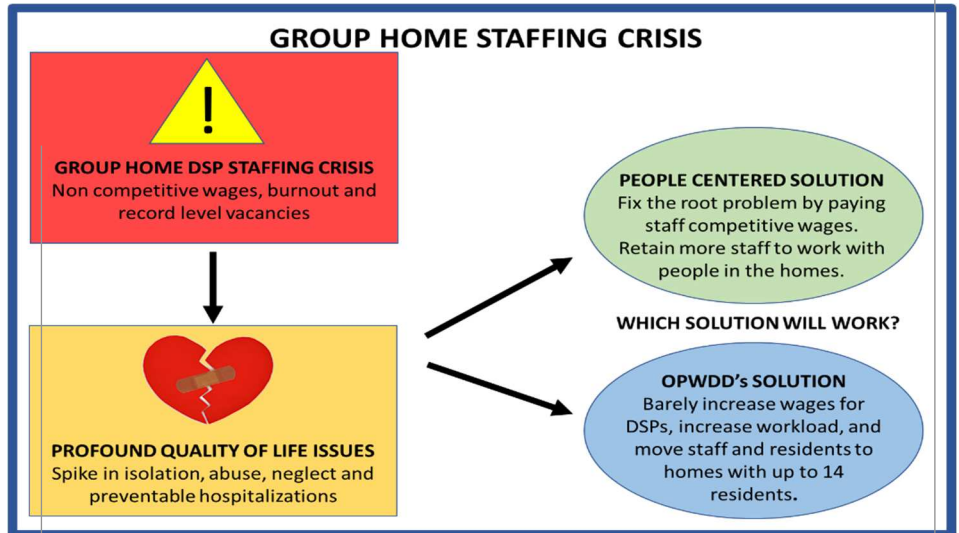
6/3/22 92nd Assembly District Candidate's Forum
 6/9/22 OPWDD 5.07 plan
 6/15/22 OPWDD Family Stakeholders
 6/16/22 Regional Leads
 6/22/22 With Families Support Services' Chairman Chris Palega to discuss 2.5 year moratorium on FSS funds

JULY

7/15/22 Statewide FSS Committee
 7/18/22 OPWDD Strategic Plan 5.07
 7/20/22 OPWDD Family Stakeholders
 7/20/22 Regional Leads
 7/26/22 OPWDD Final Plan

AUGUST

8/3/22 Westchester Institute for Human Development (WIHD) Hearing
 8/16/22 OPWDD Final Plan
 8/22/22 Regional Leads



OPWDD Emergency Placements

As many of you know, last fall our Facebook group was flooded with comments and concerns about the abrupt closure - **without any prior notice** - of over 100 OPWDD group homes due to staff shortages. This was preceded by multiple posts about mandatory lease agreements that OPWDD group home residents were being asked to sign.

What's the point of asking people with I/DD to sign a lease agreement when clearly they were not being given any tenants rights?

Unfortunately, just a few weeks ago, we were alerted to an additional 10 OPWDD residences that were being "suspended." This time an OPWDD emergency regulation was being used, but once again staff shortages are to blame.

https://opwdd.ny.gov/system/files/documents/2023/02/reg-text-2.13.pdf?fbclid=IwAR0T9_jXMFvNuJSB6fGJkSx9KhM5po2NPUWcXD8-O2iLrt6kWTPTcxAyY

At the end of the day, what this comes down to is a decade of underfunding resulting in the dismantling of OPWDD long-term supports and services. DSPs are the foundation of this system and deserve to be paid a living wage. We encourage all NYADD members to call, write or email their elected officials and beg them to acknowledge this crisis and PAY DSPs!

New York State is capable of fixing a problem that they have created. The Governor must find the funds to pay this workforce. Please take action today because **#CareCantWait**

MEETINGS, CON'T:

SEPTEMBER

9/8/22 Leads Senate Channel
with Senator Chamas
9/12/22 NYS Assembly
Hearing Live
9/13/22 OPWDD 5.07
Hearing
9/14/22 NYADD Regional
Leads meeting
9/16/22 NYADD Regional
Leads Channel Updates
9/16/22 NYDA Capitol Rally
9/16/22 OPWDD Family
Stakeholder Meeting
9/16/22 Regional Leads
Senate Action plan
9/17/22 NYADD meet with
Randi DiAntonio VP of PEF
9/21/22 NYADD State office
Channel meets with the
Justice Center
9/21/22 NYADD meets
DDAWNY to seek common
ground
9/22/22 Meeting with
Assembly Woman Lunsford
and Legislative Director
Heather Nue
9/22/22 NYADD meets with
NYS Justice Center
9/29/22 NYADD Assembly
Channel review

OCTOBER

10/3/22 NYADD Regional
Leads Media Channel
10/6/22 NYADD Regional
Leads Assembly Channel
with Assemblyman Abinanti's
Chief of Staff, Joanne Sold
10/6/22 Regional Leads State
Office Channel with Greg
Roberts of OPWDD
10/12/22 Regional Leads
10/14/22 OPWDD
Memorandum Housing
Subsidy FMF
10/14/22 With Nick Cappoletti
CEO of Life Plan and ACA
CC



NYADD Taking ACTION

The NYS budget is currently being debated. Decisions made during this time will have a direct impact on our Loved Ones this year and moving forward. This is the time for all NYADD members to step up and let our voices be heard.

One critical issue is the wages paid for DSPs in group residences across NYS. The current system needs an overdue adjustment in order to find, train and retain staff who care for our Loved Ones. DSPs and their care are the backbone of keeping our Loved Ones safe, healthy, and leading a meaningful life. At a time when staff turnover and vacancy rates are critically high, changes need to happen.

NYADD has been encouraging every member to participate in reaching out to Governor Hochel, *Deputy Secretary for Human Services and Mental Hygiene* Jihonn Kim, *OPWDD Commissioner* Kerri Neifield, *NYS Senate Majority Leader* Andrea Stewart-Cousins, *NYS Assembly Speaker* Carl Heastie, *Acting Budget Director* Sandra Beattie, as well as our individual local State Senator and our local Assembly Representative through letters, posts, tweets, emails, and calls. Some clever NYADDers have printed up extra letters for coworkers and family members to sign. Other members are printing postcards and asking friends and family to sign and mail these.

NOW is the time to be part of demanding change!
#CareCantWait

The NYADD prepared letter along with addresses for mailing is pinned to the top of the NYADD FB page. Please join our efforts to make a loud sound asking for change!



10/15/22 NYADD Regional Leads Camera Channel
 10/19/22 NYSID Celebration for Preferred Source Legislation meeting
 10/19/22 OPWDD Family Stakeholder Meeting
 10/26/22 NYADD Regional Leads meet with Assemblyman Dinowitz to discuss Camera bill
 10/27/22 NYADD Regional Leads Assembly Channel

NOVEMBER

11/7/22 Life Plan's/ACA - NY Provider's discussion
 11/16/22 NYADD Regional Leads Channel Updates
 11/16/22 NYDA Capitol Rally
 11/16/22 OPWDD Family Stakeholder Meeting
 11/16/22 Regional Leads Senate Action plan
 11/17/22 with Randi DiAntonio VP of Professional Employees Federation (PEF)
 11/21/22 NYADD State Office Channel meets with the Justice Center
 11/21/22 NYADD Providers Channel, with DDAWNY to seek common ground
 11/22/22 with Assembly Woman Lunsford and Legislative Director Heather Nue
 11/29/22 NYADD Assembly Channel review

DECEMBER

12/8/22 State Office Channel meeting with OPWDD
 12/9/22 NYADD meeting with NYDA Evan Sullivan
 12/9/22 NYADD Self Direction Channel with QCDD Self Determination
 12/14/22 Regional Leads

There are two different rallies this week that **YOU** can participate in! We need your time and energy to help make a difference!

On Tuesday March 20th at 11:00 a.m. at Dorothy L. Goosby Plaza at Town Hall. Councilwoman Missy Miller is hosting a **“Press Conference and Rally for the Fight of our Lives”**. The rally is focused on the Housing Crisis, Day Program Crisis and Staffing Crisis.

On Thursday March 23rd at 11:00 is a **“Rally for Investing in I/DD Services”**. Located at the steps in front of the Albany Capitol Building on State St. and Washington Ave.

Many NYADD members planning to attend the Albany Rally have set up meetings with their representatives to stress the need for better support for our Loved Ones and the staff who care for them. We are calling on every NYADD member to consider joining these rallies and standing for our Loved Ones who are often forgotten when it comes to policies.

SELF-ADVOCACY: WHERE I AM IN MY JOURNEY

I am a 27-year-old person with an intellectual disability who lives in my own apartment, works for a non-profit and have been an advocate most of my life.

I am the Coordinator of Self Advocacy & Community Engagement at WIHD in Westchester and am the president of the Hear Our Voices self-advocacy group. We meet each month to discuss disability issues. I am also a board member representing the Hudson Valley with the Self-Advocacy Association of New York State (SANYS). I join the monthly prep for OPWDD call to talk about all the current issues that people with disabilities and their families are dealing with in New York.



Self-advocate Brendan Klein, meets with NYS Senator Andrea Stewart Cousins

MEETINGS, CON'T:

January

- 1/18/23 OPWDD Family Stakeholders
- 1/19/23 Open House for NYS Senator Andrea Stewart-Cousins
- 1/20/23 NYADD Regional Leads Seniors 'Services and Needs
- 1/26/23 NYC Fair CM RS Settings Rule webinar
- 1/31/23 NYADD Regional Leads Seniors 'Services and Needs



SELF-ADVOCACY, CON'T:

I recently traveled to Albany and spoke with OPWDD Commissioner Kerri Neifeld, Chief Disability Officer Kim Hill and Chris Burdick legislator in the Hudson Valley. I'm advocating for people with disabilities to have better accessibility to services and improve employment options, have better living options for group homes, supportive housing and assisted living facilities for older people with disabilities.

The issue that is on my mind right now is the Social Security marriage penalty. In November I went to Washington DC for the AUCD National Policy conference. I met with Senator Schumer and I asked him why people with disabilities have to give up necessary benefits to get married. Its time for this old rule to be updated.

NYADD on the go with Suz Pgda

Why did you want to join NYADD and join the Regional Leads?

Since my son was diagnosed with IDD and ASD in 2000, providing support and advocacy for him and others who are marginalized and underserved became my life's work. Joining NYADD and becoming a Regional Lead was a natural fit. It is an amazing opportunity to collaborate with passionate people across the state and the country to shine a light on the concerns and issues in a continually underfunded system. We work together to develop strategies to effectuate change. As a wholly grass roots and voluntary group, NYADD is not beholden to any person or entity, and we organize and represent all needs of all New Yorkers with IDD and their families across the state.

NYADDers, as I call each one of us, see and experience the execution of services on the ground, for better or for worse. The motivation and collaboration of our 11,000+ members is exhilarating and there is no other group like us in the state. We assess, discuss, argue, collaborate, rally, write, call – you name it. NYADD does it – to have the Governor, the system, OPWDD, OMH, legislators, other family groups, and all constituents see and hear what is happening ON THE GROUND and work together toward positive change. NYADD is truly special and unique.

Family ideas and insights have been systematically “deinstitutionalized” since the closure of Willowbrook – we can go to meetings, but **we don't yet “sit at the table”** where decisions are made. NYADD is bringing back the family voice one NYADDER at a time.