NEW YORK ALLIANCE FOR DEVELOPMENTAL DISABILITIES

INTRODUCTION & OVERVIEW
“The future depends on what you do today.”
— Mahatma Gandhi
WHO WE ARE

NYADD is a New York State Grassroots Advocacy Group for individuals with Autism and other Developmental Disabilities.

- Created on May 7, 2020, during the COVID Pandemic, when it became evident that the rights and well-being of these individuals were not being appropriately recognized and prioritized in the pandemic response.
  - **Founding Members:**
    - Russell Snaith
    - Bob Carpenter
    - Susan Brunjes
    - Renee DeFilippis

- NYADD is 100% non-partisan and will support any elected official (or candidate) who champions our cause.
- Grassroots by design, so that there are no limitations whatsoever, on how we can drive policy and elections.
- Independent and objective from state agencies and voluntary service providers.
- A *virtual* and *virtuous* statewide Community that will endure, persist and grow for decades to come.
- The NYADD fabric is made up of all stakeholders in all aspects of the system of care across the state.
- It is power in numbers (including eligible voters), unity and persistence.
WHAT WE DO

- Advocate for funding, safety, medical, housing, education, employment, civil rights and community integration.
- Work with State Agencies and Elected Officials on Policies and Legislation to advance our cause.
- Utilize the media and other PR tools to highlight and promote our activities.

“An Epic, NYADD Watershed Moment”

Within 4 weeks of being formed in 2020, NYADD held 45 media events during a 6-week period, including this in-person Rally at the Long Island Offices of OPWDD. This was in response to concerns over the lockdowns – and the Rights of individuals and their Families and not being included in any of the NY unpause planning phases. After relentless Advocacy as seen below, OPWDD issued a series of Directives on July 15, 2020, easing restrictions and allowing family visitation with their loved ones. It also paved the way for the re-opening of Day Programs.
HOW WE ARE ORGANIZED & OPERATE

1) **NYADD Steering Committee** — *Leadership/Governance*

- Comprised of NYADD Regional Leads – geographic diversity
- 3-5+ Leads for each of the 10 Economic Regions defined in NYS
- Set advocacy focus and priorities
- Lead & comprise the ‘NYADD Advocacy Channels’
- Mobilize to address issues or concerns in the I/DD System
- Initiate, shape and drive discussion on the main NYADD FB Page
- Confers, collaborates and plans in a Private FB Group
- Represent and speak for the broader group interests
- Thought Leaders who serve as a physical presence across the state
- Each Regional Lead is an equal equity holder in the group with Admin Rights
- Meet Quarterly

- Regional Lead prospects may come forth from the main Group, who are interested, and should contact an existing Regional Lead to discuss.
- Any NYADD Member with passion and a desire to be more involved with steering and driving the Group’s focus and activities can be a Regional Lead – knowledge of the I/DD system; ie, programs and services is expected.
- Existing Regional Leads can add new Regional Leads, based on their confidence of a prospect’s fit and ability to contribute.
- A sustainable, persistent Steering Committee ensures Group continuity.
- It is expected that the current Steering Committee of Regional Leads will always ensure adequate membership in the Steering Committee and should always be actively looking to recruit, develop and maintain the group.
### NYADD Advocacy Channels

2) **NYADD Advocacy Channels** – ‘work in parallel, across Channels, on the same issues – cover the field, build relationships’

<table>
<thead>
<tr>
<th>Channel</th>
<th>Channel Key Stakeholders – Collaboration Points</th>
</tr>
</thead>
<tbody>
<tr>
<td>Provider Reps.</td>
<td>NYDA (IAC, ARC, CP State, NYAEMP, DDAWNY, ALIA, NYAII, etc.), Hud Valley Svc Prov., CCO’s PEF, CSEA</td>
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<tr>
<td>State Offices</td>
<td>OPWDD, DOH, DOB, DOL, Justice Center, Office of the Governor</td>
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<tr>
<td>NYS Assembly</td>
<td>Disabilities Committee, Speaker, Members</td>
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<tr>
<td>NYS Senate</td>
<td>Disabilities Committee, Leader, Members</td>
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<tr>
<td>Federal</td>
<td>Ancor, National Alliance for DSP’s, NYS Reps., NYS Senators</td>
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<tr>
<td>Self-Advocates</td>
<td>SANYS</td>
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<tr>
<td>Media</td>
<td>Social Media, Website, News Coverage, Press Conferences, Billboards, Rallies</td>
</tr>
</tbody>
</table>

1) Channels are comprised of Regional Leads + select NYADD Members.
2) Each Channel has a Lead and a Co-Lead.
3) Each Channel works on the advocacy prioritie/s set by the Steering Committee and engages with the Channel Key Stakeholders to partner.
4) Channel Leads will seek to engage & mobilize the large NYADD base to support & advance advocacy efforts and will provide clear guidance.
5) Channels meet as often as appropriate – considering the rate of movement and the bandwidth available.
6) Channels report status into the Steering Committee on a Quarterly basis.
7) Channels may also provide summarized updates on the main NYADD FB Page.
3) **NYADD Facebook Group** – ‘*Ongoing, real-time dialog – is the audience wrong?’* ([https://www.facebook.com/groups/NYADD](https://www.facebook.com/groups/NYADD))

1) 10,300+ Members and growing
2) Posts and Discussion Threads ebb and flow freely (though monitored) to enable information and resource sharing, communication, collaboration and dialog.
3) There is a raw, spontaneous element to this that provides value in the sense of a mirror or barometer for what is going on out there.
4) As such, it may not all be 100% factual, but based on opinion, emotion and limited information or knowledge.
5) But there are self-correcting mechanisms as people see posts and comment.
6) The value is in the insights (nuggets) and the audience response.
7) Our amazing Moderators manage the Group, assist new and existing members and ensure that the NYADD Rules are followed.
8) Steering Committee Members – Regional Leads are Group Admins.

4) **NYADD Special Focus Groups** – ‘*all hands-on deck’*

1) Cross-channel and created to apply concentrated, broad and deep focus on a burning issue – eg. NYADD Camera Crew, Employment, etc.
2) May have Reps from some/all Channels + additional stakeholders needed to achieve objectives. Mobilize large NYADD base when needed.
3) May be of limited duration.

5) **NYADD Website** – *(nyadd.org)*

1) Provide relevant and useful information about NYADD – an organized, professional image to the public.
2) Enable members to register and allow us to collect some data.
3) Store key documents.
4) Enable Donations.
5) Collect member/user feedback, input, questions.
### NYADD REGIONAL LEADS – STEERING COMMITTEE MEMBERS

<table>
<thead>
<tr>
<th>Region</th>
<th>Lead</th>
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</thead>
<tbody>
<tr>
<td>1 Western New York</td>
<td>Peter Zummo, Susan Davison-Netzel, JR Wade (Advisory)</td>
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<tr>
<td>2 Finger Lakes Region</td>
<td>Heather Ash Burroughs, Karen Duboy</td>
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<tr>
<td>3 Southern Tier</td>
<td>Shailene Crowley-Fellows</td>
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<tr>
<td>4 Central New York</td>
<td>Kevin Carman</td>
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<tr>
<td>5 North Country</td>
<td>Vacant</td>
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<tr>
<td>6 Mohawk Valley</td>
<td>Steve Gonyea, Ron Loubier</td>
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<tr>
<td>7 Capital District</td>
<td>David Guerrera, Sara Berg (Advisory)</td>
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<tr>
<td>8 Hudson Valley</td>
<td>Tara Klein, Barbara Carson Todd, Katy Foxen-Faivre,</td>
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<td>Susan Sollenberger-Havko, Suzanne Prigoda, Stephanie Brenner</td>
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<tr>
<td>9 New York City</td>
<td>Gail Hamlin, Marilyn D’Agostino, Simcha Weinstein</td>
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<tr>
<td>10 Long Island</td>
<td>Erin Rach, Ellen Alexander, Marianne Barbera, Eileen Benthal, Angela</td>
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<tr>
<td></td>
<td>Devincenzi, Stacey Schultz Wohl, Pam Frank (Advisory)</td>
</tr>
</tbody>
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**Founding Members:**
- Russell Snaith
- Bob Carpenter
- Susan Brunjes (Moderator)
- Renee DeFilippis (Moderator)

**Moderator**
- Beverly Roach

**NYADD**

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![Regional Map of New York State](image-url)
## NYADD Advocacy Channel Composition

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<thead>
<tr>
<th>Channel</th>
<th>Lead</th>
<th>Co-Lead</th>
<th>Member</th>
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<td>Provider Reps.</td>
<td>Suzanne Prigoda</td>
<td>Russell Snailth</td>
<td>Ellen Alexander</td>
<td>Gail Hamlin</td>
<td>Marianne Barbera</td>
<td>Barbara Carson Todd</td>
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<td>State Offices</td>
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<td>Tara Klein</td>
<td>Karen Duboy</td>
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<td>Tara Klein</td>
<td>TBA</td>
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CONTACT & OTHER INFO.

For NYADD Members and others, all inquiries, questions and concerns should be directed to a NYADD Regional Lead in your Region. They are the key point of contact for NYADD for each Region.

Be sure to follow NYADD on Twitter: @nyaddcares

Footnotes & Disclaimers:
1) NYADD Leads volunteer their time, skills and passion and are not paid.
2) NYADD is a Grassroots organization and has no legal standing.
3) NYADD as a Group, nor any individual NYADD Leads takes any responsibility for the actions or comments of any other Lead or NYADD Member in public or private forums or media.
4) NYADD makes a good faith, best effort to Moderate public discussion and comments so as to ensure respect and professionalism.