

Care Management Alliance

NEW YORK

SHARED STORIES: A Panel Discussion with Disability Advocates

Tue Sep. 16, 2025 | 6:00-7:00pm

Virtual Event

Shared Stories

A Panel Discussion with Disability Advocates

Who is CMANY?

The Care Management Alliance of New York, Inc.

In every county of New York State, Care Coordination Organization/Health Homes (CCO/HHs) support individuals with Intellectual and/or Developmental Disabilities (I/DD) through all stages of life. CCO/HH Care Managers coordinate services and supports to address all social determinants of health, including health care, employment, housing, community relationships and resources for economic stability.

This includes over 75,000 individuals who live at home and depend on coordinated services, and over 36,000 individuals who require 24/7 care and oversight.

Our mission is to ensure that all New Yorkers with Intellectual and/or Developmental Disabilities can continue to access services for fulfilling, meaningful, and inclusive lives in our communities.















Shared Stories

A Panel Discussion with Disability Advocates

THANK YOU FOR BEING HERE!

Tonight's Agenda | 6:00-7:00pm

- Welcome & Housekeeping
- Welcome to our Hosts
- Panelist Introductions
- Story Sharing from our Panelists
- Open Forum (time permitting)
- Closing / Wrap Up

Housekeeping

- Attendees are urged to provide comments in the CHAT feature.
- All attendees are muted
- Hosts & Panelists have camera and mic accessibility
- Hosts will attempt to get to as many comments as possible.
- Copy of slides and recording of session will be made available soon

Today we have a panel of Advocates from across the state who will share stories about their advocacy journey, experiences with legislators, and why it is important to raise awareness about the needs of the IDD community!

WELCOME OUR HOSTS:

Veronica is a self-advocate serving on CDNY's Advisory Board, Designated Representative Committee and as an employee with the title of "Individual & Family Liaison". As an advocate she has provided testimony at state hearings, hosts a monthly Peer Empowerment Group, and has been featured on both radio and TV.





vcrawford@caredesignny.org

Veronica on LinkedIn



MAX DONATELLI

Art of Advocacy

Max on LinkedIn

Max is a proud parent who, along with his wife Joyce Donatelli, has two beautiful children. Connie and Craig. Craig is 34, has Down syndrome, and lives semiindependently and works in competitive employment. Max regularly writes articles in the media and speaks publicly on advocacy topics. Recent advocacy awards include: NY Alliance for Inclusion and Innovation, Community Advocacy Award, and NFJC Lana Benatovich Lifetime Achievement Award. Max is the co-founder of the Art of Advocacy.

Welcome Panelist: STEVE GONYEA



Steve Gonyea is a dedicated father and lifelong advocate based in Central New York (Utica area). He is the biological father of a 35-year-old son with autism, and the adoptive father of three teenagers with disabilities—including profound autism and trauma—who came to his family through the foster care system. In addition, Steve has served as a respite dad and a juvenile justice dad for children from other state systems, all of whom have diagnoses of Intellectual and Developmental Disabilities (IDD).

Steve's advocacy journey began 31 years ago when his then 4-year-old son was struggling without a clear diagnosis or support. That experience led to a diagnosis of autism and sparked a lifelong commitment to improving systems for children and families with IDD.

He has served on the boards of the Family Advocacy Center, ARC College Works, and the Utica Center for Development. Steve built an "Autism Barn" to support his son and other community members, and launched the Ability Bus initiative—providing transportation for disabled children and families through the Veterans Outreach Center. This initiative is now evolving into a national movement, with plans to expand Ability Buses across New York State and eventually nationwide through WorthDoing.org in collaboration with a national film company.

Steve currently serves as the Statewide Lead for NYADD and was recently appointed as the New York State Autism Chair for the National Council on Severe Autism (NCSA). He is also the founder of *Finding Common Ground*, a statewide disability-focused podcast that amplifies diverse voices and perspectives. Despite his many roles and accomplishments, Steve considers his most important title to be Dad.





Welcome Panelist: BIN FENG



For over 20 years Bin has worked to help Chinese families supporting Autistic children, in both China and United States. He volunteers and serves on various committees and initiatives in support of the IDD community. These include - Autism Speaks, NYS Council on DD, and the State Rehabilitation Council. He is a 'Fathers Support Coordinator' for Parent to Parent, and a Chair member of Care Design's Family Advisory Board. Bin is a co-Founder of the non-profit organization *Project Ready*.

His advocacy started with trying to understand and help his son with autism spectrum disorder and ADHD. With a desire to help other families with autistic children, particularly those within the Chinese and Asian American community in NYC.



Welcome Panelist: BJ STASIO



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BJ Stasio is the former President of the Board of Directors of the Self-Advocacy Association of New York State (SANYS), a position to which he was elected by his fellow self-advocates and peers around New York. He has also been employed by OPWDD for over 20 years, currently a Peer and Family Advocate, working on person-centered planning, voting issues, and self-determination training and education. Additionally, he has served on the board of the National Federation for Just Communities of Western New York, the Disability History Museum Board, and co-founded a non-profit organization Buffalo Racin', focused on getting people with disabilities involved in 5K races. BJ has been actively involved with advocacy for much of his adult life. Recently, he co-created a not for profit, the <u>Art of Advocacy</u>, <u>Inc</u>. In 2025, Bj received the Hinsburger Humanitarian award from the National Alliance of Direct Support Professionals.



Welcome Panelist: RYAN WILLIAMS



Ryan is a 31-year-old self-advocate that receives care management services and has a self-direction plan. It is important to Ryan to be independent and to encourage others to. He lives in his own apartment with the support of Community Habilitation. He works at Syracuse University in one of the dining halls for many years. Ryan has been an advocate for individuals with autism throughout the Syracuse community.

Ryan is an author and writer. He has given speeches to local organizations to help promote self-advocacy through his journey as a person with Autism. He speaks about the accomplishments that autistic people have done for the world and is educating people about autism. Ryan founded the Autism Crusaders in 2015 which is an autism activist movement for educating about how people with autism have contributed to society bases on their skills as autistic individuals. Ryan's goal with Autism Crusaders is to help protect the rights for people with autism to live full hard working and productive lives. He wants to grow Autism Crusaders to be able to speak across the country to reach many people about living with Autism.

Ryan is an active member of the Prime Care Coordination Individual and Family Advisory Board. He will also be joining the Prime Care Coordination Board of Directors later this year. Ryan is also an avid golfer!



Welcome Panelist: CHRISTINA SILVA-SOTO

Christina Silva-Soto serves as the Director of Member and Family Engagement at Tri County Care, a Care Coordination Organization (CCO). Her most important role, however, is being mom to her 11-year-old son, Oliver, who has multiple disabilities.

When Oliver was diagnosed around age one, Christina faced the overwhelming challenge of navigating supports and services with little to no guidance. At the time, resources were not readily available, and she was left to figure out the system on her own. Determined to secure what her son needed, she immersed herself in learning about services and supports, eventually navigating the OPWDD eligibility process and even applying for Medicaid independently, all before the creation of CCOs. Although her professional background is in business, Christina found the process difficult and isolating. Out of that experience, she began hosting community support groups several evenings a month to help other families facing the same challenges.

Her passion to ensure no family feels alone on this journey led her to join Tri County Care, where she now helps families from start to finish, drawing on her lived experience as both a parent and an advocate. Christina and Oliver are active voices for the disability community; just this summer, Oliver met with several New York State legislators, including Senator Pat Fahy, Chair of the Disabilities Committee. He even wrote the Senator a heartfelt letter explaining how vital his services are, continuing the family's advocacy for the most vulnerable.



Visit Website



Welcome Panelist: CHRIS MORRIS



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Chris is a strong self-advocate. He started his advocacy journey in 2017 when he took the step to move out of his aunt's home and into a voluntary operated IRA. Since that time, he has taken the lead in decisions regarding his housing and programming. He has tried many different services and supports to curate the life he wants. He has also become highly involved in his medication regimen and actively advocates when he feels changes are needed or he wants to explore new options for treatment.

Chris is the 2025-2026 president of the self-advocacy committee at the Arc of Delaware County. He also served in this role for the 2023-2024 term. He has participated in two rallies in Albany to advocate for no cuts to Medicaid or Medicare in the last year, as well as spoken with Congressman Molinaro in 2023 regarding Social Security asset limits. Chris has most recently joined the Southern Tier Connect Advisory Board to help advocate for the needs of members and be able to make an impact the direction of the organization.



Welcome Panelist: Michele Lawton



Michele Lawton is certified as a NYS Housing Navigator and a Self-Direction Broker and also assists individuals with access to OPWDD and SSI Eligibility and all adult disability services. She works with individuals and families to assist them to find or create housing and residential supports. She also acts as an advocate for individuals and is a liaison with OPWDD to facilitate residential placements and independent living for her clients. She has been a certified NYS Housing Navigator for almost 11 years, graduating in the inaugural class in December,2014, and she has been a Self-Direction Broker for 9 years with a concentration on housing and supports and independent living. Michele has completed the Cornell Course for Work Incentives Planning and Utilization for Benefits Practitioners Certificate Series and assists with Benefits Planning and Navigation in the areas of SSI/SSDI, Medicaid, Medicare, and work incentives as integral parts of a person-centered Housing and Support Plan. She has assisted in placing over 50 individuals with disabilities in Certified Housing through the OPWDD Priority system and has also assisted to create non-certified independent housing and living settings using self-direction for over 30 individuals with disabilities, including students over 18 living on a college campus. Her educational background is in public accounting, and she worked at Price Waterhouse in Rochester and New York City for 8 years after graduating from St. John Fisher College with a BS in Accounting. She founded Special Needs Advisors LLC with her partner, Musa Klebnikov, in 2021. Michele and Musa founded Special Needs Advisors to assist people with intellectual and other disabilities and their families to create housing and other supports looking to long term sustainable solutions.

Michele is also a Board Member of the Society of St. Vincent de Paul in Ossining, NY, has served on the Board of Cardinal McCloskey Community Services, in Valhalla, NY, and has been involved in many fundraising endeavors for people with disabilities. She is a member of the Family Advisory Board of Advanced Care Alliance (ACA) and is a member of the PADD Advisory Committee for Disability Rights NY.

Michele has 5 children, including her son with severe autism who is an active participant in the community and lives in a specialized Supervised IRA owned and managed by Cardinal McCloskey Community Services (CMCS) which she helped create. Michele has been advocating for her son, Jack, for 36 years. Jack has a history of challenging behaviors and his struggle and the struggle of his family to find and/or create the services and supports he needs to make progress, meaningfully engage in the community, and live as independently as possible sparked Michele's mission to help others. Jack's love and light has inspired the founding of Special Needs Advisors and its mission.



When asking our Panelists to share their stories, we posed several questions to them. They include:

- How did you get started with your Advocacy journey?
- Why do you feel it is important to use our voice with lawmakers?
- What would you say to someone who is tentative or scared about taking extra steps to advocate?
- Give us an example of an experience you've had when engaging a legislator? What can we expect during those meetings?
- Share an example of the impact your advocacy has had!
- What is a final message or vision for advocacy that you would like to share?

Story Sharing...

- 1. Steve Gonyea
- 2. Bin Feng
- 3. BJ Stasio
- 4. Ryan Williams
- 5. Christina Silva-Soto
- 6. Chris Morris
- 7. Michele Lawton

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WRAP UP & CLOSING

- Remember to advocate and raise your voice about the issues important to you.
 You are not alone we are in this together!
- Thank you to our panelists for sharing their stories with us. You are inspiring!
- Thanks to all of you for joining us tonight
- Please be sure to join us in October & January for more information sessions
- This Presentation will be sent to registrants and will include additional slides with special Advocacy RESOURCES for you to explore
- Recording of this evening's event will be shared on several CCO websites for future viewing, along with transcripts for translation and additional accessibility

SAVE THE DATES October 16th 2025 6-7pm

January14th 2026 6-7pm

Guest Speaker Carolyn Kerr from the legal firm Brown & Weinraub will provide updates to Medicaid along with information on key legislative races and district representatives, as well as tips on how to advocate and what to expect during meetings with lawmakers.

Subscribe to your CCO's **Newsletter for Registration** Information as dates get closer!



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NEW YORK

RESOURCES



- Project Ready Website <u>Project Ready</u>
- Art of Advocacy Website <u>Art of Advocacy, Inc.</u>
- Finding Common Ground Podcast Website <u>Finding Common Ground</u>
- NY ALLIANCE for Inclusion & Innovation Guide to Advocacy
 <u>https://nyalliance.org/images/downloads/ny_alliance_guide_to_advocacy___2024.pdf</u>
- ANCOR Advocacy Toolkit https://www.ancor.org/advocacy/toolkit/
- Self Advocacy Association of NY State (SANYS) https://sanys.org/
- Parent to Parent of NY State https://www.ptopnys.org/
- Special Olympics of NY State https://www.specialolympics-ny.org/
- Peer Empowerment Group (Monthly connection for Self-Advocates)
 <u>https://caredesignny.org/events</u>