

# Care Coordination Organizations (CCO) & Covid-19




## Our Champions V

The seven New York State Care Coordination Organizations (CCOs) provide essential planning, coordination, advocacy and support to over 107,000 New Yorkers with developmental disabilities, including intellectual disabilities, cerebral palsy, Down syndrome, autism spectrum disorders, Prader Willi syndrome and other neurological conditions.

Individuals with intellectual and developmental disabilities represent the most complex and vulnerable population in New York State. Most children and adults with I/DD have co-occurring medical, behavioral health, physical and

developmental disabilities and conditions. The experienced and well trained CCO care managers use advanced person-centered planning approaches to assist people in receiving the quality healthcare, disability and community-based support services they need to lead successful lives in our State.

While promoting community inclusion and integration, Care Coordination Organizations provide an invaluable safety-net function, protecting this most vulnerable population. The following anecdotes reflect the noble work that Care Managers do on a daily basis.



## **Successful Advocacy and Collaboration Result in Positive Health Outcome for COVID Patient**

Karen, (names have been changed to protect the privacy of the individual) is a 59-year-old LIFEPlan member with a mild intellectual disability who lives independently. Karen began having some mild COVID-19 symptoms including a low-grade fever and stomach distress. She shared these symptoms with her Care Manager during her weekly check-in and her Care Manager advised her to call her Primary Care Physician (PCP). Her PCP told her to take Tylenol and rest at home, but her symptoms worsened, and the following week, her PCP tested her for COVID-19. While waiting for the results, her fever spiked and she developed a severe cough, so Karen called 911 on her own. The EMS provider who came to her home said he would not take her to the hospital because he feared that she would only be sent home.

When Karen's Care Manager checked on her the next day, she learned that Karen's test result was positive, but she could also hear through the phone that Karen was having significant trouble breathing. Karen reported that she was unable to eat or drink and was feeling lethargic. The Care Manager suggested calling 911, but Karen was hesitant because of her previous experience being told by EMS that she would not be admitted.

At this point, the Care Manager reached out to the Clinical Team at LIFEPlan. The team reviewed the case and advised the Care Manager to speak directly to the EMS provider. With that, Karen was transported to the local hospital. Because Karen has a strong relationship with her Care Manager, she called the Care Manager from the hospital in agitation, as they were in fact not planning to admit her, despite being dehydrated, with a high fever, shortness of breath, and still unable to eat or drink. They had given Karen fluids, but were insistent that she go home and call 911 again if her symptoms worsened.

At this point, the Care Manager solicited the help of the Clinical Team's Registered Nurse who then called the hospital and spoke directly to the hospitalist physician in charge of Karen's case. The Care Manager explained why it was unsafe to discharge Karen, as she may be challenged to self-monitor her symptoms, and that she was at significant risk of complications due to mobility issues. Reluctantly, the physician admitted Karen for monitoring overnight. (The physician admitted that he did not know much about OPWDD services and assumed that "someone" would be attending to Karen's medical needs in person).

Karen ended up staying in the hospital for three nights and received IV antibiotics, fluids, and oxygen. She was then discharged as her symptoms abated and, most importantly, was able to tolerate food and water. Karen is now home and has been symptom-free for the past week.

This is a great example of successful advocacy for a member, collaboration between Care Management and the Clinical Team, and the importance of regular check-ins on our members who live independently.

## Showing Care via Food Deliveries

A Director of Care Management at ACA/NY was recently made aware of a campaign called “Feeding Families”. This campaign was sponsored by local restaurants on Long Island; Juventus Pizza Ristorante, VERDE Kitchen & Cocktails, and Selden Pizza to provide family style meals to needy Long Island residents.

The Care Management Director worked within their region and coordinated 22 Care Managers to identify families that would benefit and were interested in the campaign. The Care Management teams then proceeded to deliver the meals to families while practicing social distancing and wearing face masks and gloves.

The feedback from the families was heart-warming and amazing to hear, as many of these families have been unable to obtain meals like this since the pandemic started and they expressed gratitude to the Care Management staff for thinking of them.

Stories like this show how Care Managers have integrated community supports to help people with I/DD and their families during the pandemic.

## Phone Support

At a time when our worlds have been turned upside down, even the smallest actions have the potential to make a big difference.

Erica, a Care Manager at Southern Tier Connect, has been working with a young school-age individual who lives with his parents. This young man is very routine oriented, and found the adjustment of being home difficult, with schools being closed and his community habilitation postponed. His mom has physical limitations and is not able to play with him the way he would play with other kids at school.

As a means of extra support, Erica spoke with him and suggested that he call her when he needs someone else to talk to. She also encouraged both him and the family to reach out to his counselor at the Article 16 clinic when needed.

Erica reports that he has reached out to both his counselor and herself and, after talking to both, he is doing better at home. Additionally, Erica did some research and compiled a list of educational websites, along with a list of aquariums, zoos, and museums that are doing virtual tours, and sent the list to his mom. They are doing these virtual tours and games together, easing their daily lives during this difficult time.

# “The Pandemic Challenge”



When the COVID-19 pandemic broke out and began spreading in the US during the early months of 2020, many were in a state of disbelief until its fast pace became a frightening reality. As it became an apparent fact that our beautiful world is in turmoil as a result of this dreaded virus, an ambience of gloom and fear reigned. Jobs were lost, businesses folded up, and investments shrunk. States and communities were locked and shut down entirely resulting in friends distancing, loved ones separating, and families torn apart. Everybody deserted the natural human craving of physical social interaction and supplanted it with haphophobia: fear of touching another or being touched by others.

The pandemic has become an affliction that suits the statement "survival of the fittest." As this novel Covid-19 disease ravages the world, it hits hard on the vulnerable population, including the older people and adults with pre-existing conditions. The older population already faces a different set of challenges linked with long-term physical and chronic conditions, and this pandemic has only added more angst to it.

It is in this regard that Walter Owusu, a Care Manager of Tri-County Care, took a purposive action to safeguard their livelihood, with thoughtful action and understanding of welfare for the elderly.

**“We believe that in the face of such examples of human compassion, sympathy and extra care, this virus will succumb...”**

Walter availed himself to help the aged cope and lessened their struggle by providing food items which are an essential need under the stay at home order during this pandemic.

It all began when Walter started an Instagram live show where doctors and other clinicians joined to talk about COVID-19, its spread, infection period, and other developments regarding the pandemic. The strength of the explanatory power from the health professionals prompted Walter to initiate a collective action to donate groceries for the aged in his community, who are unable to go out and access needed staples. A group was formed to spearhead this challenge.

At the end of each show, watchers of this live Instagram show donate money to help buy groceries for the community's elderly members. Names and addresses are provided by the people watching, to deliver food for the suggested recipients. In partnership with some local businesses in the Bronx, Walter and his group sometimes get foodstuff and groceries as donations. They have been able to reach out to over 50 homes in the Bronx so far. This action, which he termed "The Pandemic Challenge," started very small in his Bronx-based community, but has now reached Virginia, Ohio Columbus, and Worcester, Massachusetts.

Walter's Instagram live show became an important pivotal tool because he impacted the alacrity at which "The Pandemic Challenge" expanded from micro-level towards macro. Walter and his group are steadily gaining recognition for helping needy individuals. Through their continuous live chat with the health professionals, PIX 11, a media outlet, acknowledged their importance and invited Walter and two other members for an interview. In the interview, which was screened live on TV, Walter elaborated on the rationale behind the formation of "The Pandemic Challenge," gaining lots of positive feedback.

Walter's missive took off way past his original intentions; this fact highlights the passion and willingness to take his work detail beyond what is expected of him. He had a vision, and ran with it. Walter's story is a prime example of a Care Manager extending supports towards individuals with I/DD that goes past the job description, a phenomenon seen daily at Tri-County Care and other CCO's. We believe that in the face of such examples of human compassion, sympathy and extra care, this virus will ultimately succumb.



## **The Many Hats a Care Manager Does, including Solving a 30-year old Adoption Case**

*It is the best feeling in the world when you achieve a daunting goal that at the time seemed unsurmountable. This is how one Care Design NY Care Manager describes an almost one year- long project.*

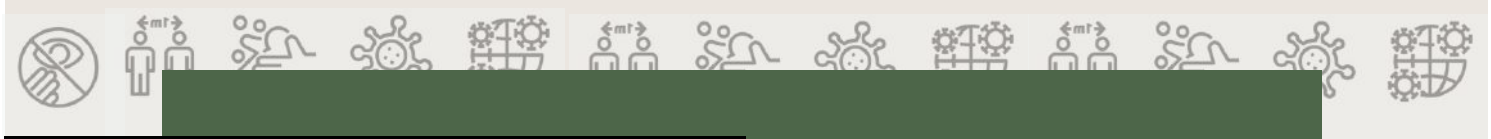
*It was last July when C. (for purposes of anonymity, we'll call her "C."), an individual that Care Design NY supports, received a letter from the U.S. Social Security Administration stating that her permanent resident card, aka "green card", was no longer valid for Medicaid eligibility. She was informed that the long-term benefits that she depended upon for support would be suspended. She had one year to produce U.S. citizenship documentation, or she would have to reapply in seven years.*

*The panic waves that had once rendered C. helpless but had subsided through medical and mental health treatment, came rushing back. For years, she battled a debilitating condition diagnosed as post-traumatic stress disorder that left her unable to perform even basic tasks on some days. This was a result of abuse and neglect at the hands of her American adoptive parents.*

*She had no family that she could turn to for help. All ties with her birth parents were severed when the international adoption agency processed the paperwork for the American couple when she was only a few months old. She had lived with her adoptive parents until the county's child protective services intervened. At the age of 14, she entered the New York foster system.*

*On her 18th birthday, she declared her independence as an adult and became eligible for Medicaid. This would open a new chapter in her life with an opportunity to receive medical and mental health benefits and a chance for a healthy and happy life. She began to receive long-term supports and services (LTSS) from the county's Arc for medical, mental health, and a variety of other services. These services, tailored for her unique disability needs, helped to establish a foundation for a quality life.*

*It came as a shock last summer, the Care Manager recalls, when C. called him. The full impact of what this non-eligibility of benefits letter would mean and how it*



***would negatively impact not just her quality of life but, quite frankly her survival, was frightening. Everything that C. and the care management team had worked so hard for all along was in jeopardy.***

***They went to work trying to unravel an international adoption process. She did not have documents with clues to the name of the international adoption agency who would have her official birth and adoption records and her foster mother was seriously ill in the hospital.***

***The Care Manager recalls that there are moments in your life that you look back upon and wonder how you possibly accomplished what seemed to be at the time an impossible undertaking. To quote Nelson Mandela, “It always seems impossible until it’s done.”***


***“ It always seems impossible until it’s done. ”***

***He consulted with the Care Design NY Benefits and Entitlements director. The expertise of the Benefits and Entitlements director helped to forge a plan for the next steps. They also consulted an immigration attorney who said that this was a new development; an individual with a disability who did not have proof of citizenship.***

***With advice on next steps, which included identifying when she was adopted and the name of the international agency, they feverishly went to work. They made numerous phone calls leaving message after message to the U.S. Immigration authorities and the county.***

***It would be weeks before a county worker would contact them. He was very sympathetic with the situation and remembered the case from years ago when the young woman was rescued from unfit adoptive parents. He identified the next step which would require consent for the sealed records to be opened.***

***They found the name of the international adoption agency in the county’s child protective service records and they were hopeful. But this led to a dead end. The agency had moved out of state to Oregon, almost 3,000 miles away. With the distance and time zone difference, he lost count of the number of phone calls and***





***messages he left urgently, pleading for someone to help. He stated, “I called incessantly. I wanted to be on their radar.”***

***Days and weeks went by and it was challenging to keep hope alive. He stated, “I realized at one point during the long ordeal waiting for a response that I’m not superhuman, but just an average person doing their job.”***

***Then, months later, the COVID-19 pandemic hit the U.S. and it seemed that there would never be a breakthrough in the case given the amount of global turmoil. But a crack in the case appeared and then light came pouring in. He vividly recalls the day the adoption agency representative called, stating, “We found it!” The agency then sent C. a large envelope containing a document written in beautiful calligraphy, officially stamped, and signed. She had been a U.S. citizen since she was one year old. The bureaucratic nightmare was over. The adoption agency wrote a letter to the Social Security Administration and just two weeks ago, ten months after the loss of benefits notification letter was sent, C. called the Care Design NY Care Manager exclaiming into the phone, “Are you sitting down? I received my check today and my SSI benefits have been reinstated!”***

***He only remembers seeing a very bright light as if coming out of a long and dark tunnel. “This was a realm,” he stated, “where I’ve never been before; navigating immigration, social security, international adoption and a myriad of other details important to cracking the case.”***

***His Regional Director commended him on his perseverance and dedication stating, “The heart of a Care Manager has persistence, compassion, and curiosity to keep on going and to advocate for the best possible outcome. Care management is all about a strong heart and courage; knowing the person you support, respecting their wishes, bridging trust and bringing in resources when necessary to help. He exemplified all these traits, always advocating for what was right and just, and understanding what would make a difference in this member’s life. He is truly a superhero and a wonderful advocate for the individuals he supports.”***





## Technical Support

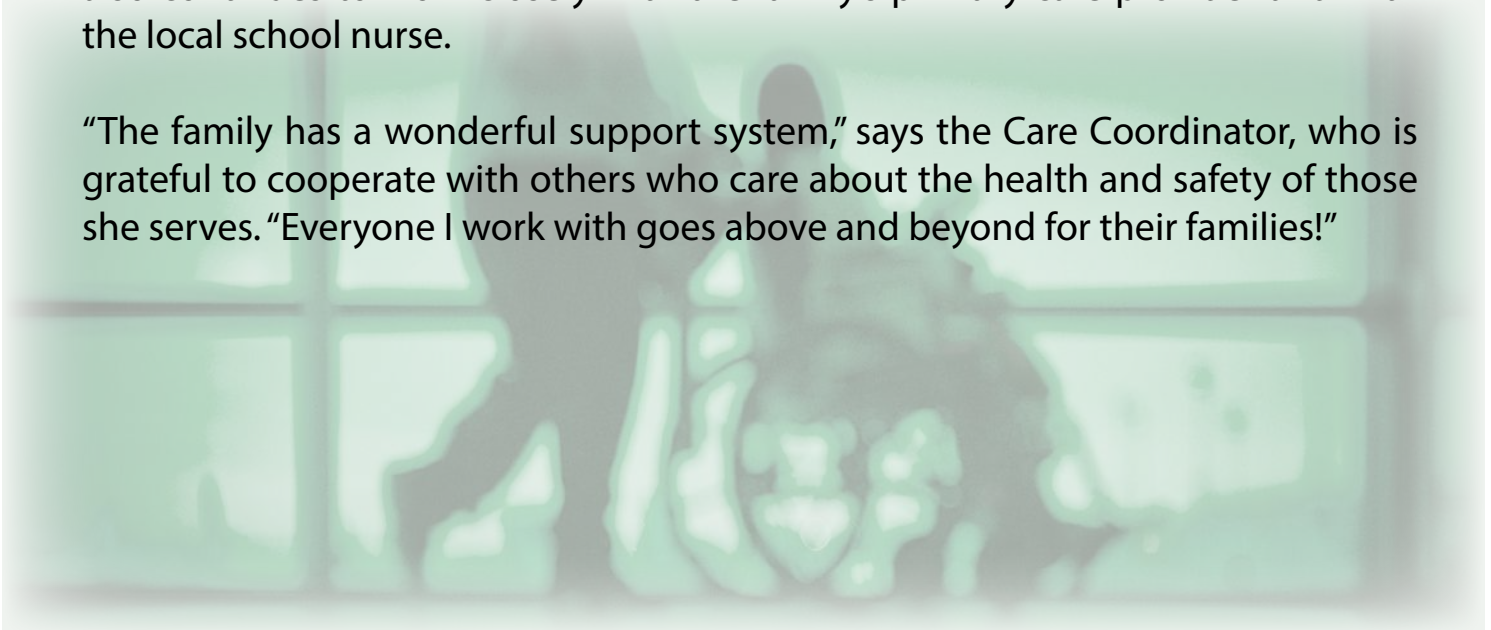
Many families have additional needs than usual because of the COVID-19 crisis. A Care Coordinator from Person Centered Services supports several people from the Amish community in her area. One of the Amish families she serves has a child with serious medical needs who required a tracheotomy. The Care Coordinator has worked very closely with the family's primary care provider to get the child all of the services that she needs, both at home and at school.

The child uses a suction machine on a daily basis, which requires oxygen. Since the family is Amish, they did not have electricity in their home. They previously used equipment connected to a generator, which had very expensive costs associated with it.

The family was able to get approval from their community to have electricity installed. Once approved, the Care Coordinator assisted them with finding a free inspector and a discounted electrician. Labor costs and supplies were approved through family reimbursement programs.

Because of the virus, more electrical updates will take place in the summer. The Care Coordinator continues to help with referrals, assisting with family reimbursements for certain expenses. She recently secured an overnight shipment for the family so they could receive necessary medical supplies. She also continues to work closely with the family's primary care provider and with the local school nurse.

"The family has a wonderful support system," says the Care Coordinator, who is grateful to cooperate with others who care about the health and safety of those she serves. "Everyone I work with goes above and beyond for their families!"



## Beyond the Call of Duty

When someone becomes a member of a Care Coordination Organization, it's not just the individual that is looked out for. Oftentimes, Care Managers get to know their extended family as well. Prime Care Coordination prides itself on being there for every aspect of a person's life journey, and that includes any hardships that may come around.

One Care Manager at Prime Care Coordination mentioned how she was checking up on families in the beginning stages of the COVID-19 crisis, when she realized the struggles some were going through. On one particular call, the Care Manager spoke to

Sue, a mother of one of our members. She said her son was still out of town with his dad, but that she was home alone and was sick. Due to Sue's health conditions, she was unable to leave the house, and needed groceries.



Our PCC Care Manager didn't hesitate to help, and reached out to CHOW (The Community Hunger Outreach Warehouse) in Broome County to see if

they could help. The Care Manager was able to speak with someone who proceeded to set up a delivery of five days worth of shelf-stable items for Sue, and she received the items at her doorstep without a problem.

During this time, Care Managers are learning new ways to connect with those they support and help families in need; they're constantly finding new ways to help out. The

compassion in the hearts of all our Care Managers and employees is what keeps us going every day and we're so thankful for the consistent personalized support they provide.



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1-518-235-1888



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