

Family and Care Coordinator Interview

This piece reflects the experiences of the Johnson family who were supported by Care Coordination during the time of COVID-19. It addresses the hurdles they faced and the positive outcomes Care Coordination can deliver, even during very challenging times. The parents have one daughter and two sons, each with their own needs. They have given permission to share this interview. Names and some identifying details have been changed to protect the privacy of individuals. Comments are in the words of the mother, Helen.

Knowing that there could be many challenges that a family could endure during COVID-19, what was a challenge that your Care Coordinator assisted you and your family with, and what was the outcome?

COVID-19 hits

When school was in session, we had several services that helped. Then COVID-19 hit, and we get a call that school will be out until spring vacation. I was dreading spring vacation already. Two weeks into quarantine we heard that school would not begin again, and we felt adrift in the ocean. Google Classroom worked sparingly, but the speech therapist and the special education teacher didn't get connected to Google Classroom until two months into it. It seemed like special education students were left hanging dry.

And at the end of the school year, the mental health therapist said 'This will be our last session'. Even after our daughter shared feelings of self-harm, the mental health therapist ended the call. Two weeks later she went to the emergency department. But it was the needs of my youngest son that got us connected to our Care Coordinator. Our son was just so angry and would sometimes hit himself because he was so frustrated. Even though he was only six years old, he put holes in the wall. He was thought to have autistic tendencies and Attention Deficit and Hyperactivity Disorder (ADHD). However, he was never formally diagnosed, only for medication purposes, and was given the diagnosis of ADHD and Disruptive Mood Dysregulation Disorder (DMDD). We as his parents received the information that due to both his siblings and his parents being on the autism spectrum, as well as having other existing co-disorders, the treating medical team gave the youth a diagnosis based on a family history of disorders.

First things first

After the first Child and Family Team meeting, one of the first things our Care Coordinator did for us was get our son psychological testing. She saved his life. He was diagnosed with receptive and expressive language disorder, which means that he has a hard time understanding what people are saying, especially feelings and thoughts and he also has a hard time expressing himself. It makes sense now that he would get angry because he was so frustrated that he couldn't understand and express his feelings in words. We had providers who said they were making a referral to another provider, and I didn't know that they hadn't made that referral. It wasn't until our Care Coordinator asked them if the referral was

made that we realized it was never done. So, in the next Child and Family Team meeting, a date was set about when the referral needed to be done. During COVID, providers were not accepting new clients or able to provide transportation. But our Care Coordinator got us connected with a great team of people.

How do you feel your family's involvement, in the process of Wraparound, created opportunities for them to access supports and services in your community?

We felt like we were in this gray gap between Birth to Three (which is great), and then nothing much until age 13 when people think children can take more advantage of therapy. What made things even harder was that we had HUSKY B where we had to figure out how to have services paid for like Applied Behavioral Analysis (ABA). Our Care Coordinator connected to the providers and if they weren't accepting new people, she would connect to the next provider. She did the leg work. Our whole family life has changed. My son now plays with his siblings and likes to play board games with his father. Before, he never spent time playing with his father.

I am connected to the New Britain Collaborative, an amazing group of people that support people who are dealing with varying issues, and I am also connected to providers and resources that are in my community. Amazing organizations that are there when you need them, and support groups for parents who get it when we celebrate the small wins, like my son eating bread with the crust on it or when my older son just made his first friend in a new school.

Did your family experience a positive change during COVID-19, with the assistance of your Care Coordinator?

Having six people in the house who are dealing with different disabilities was tremendously hard. Our Care Coordinator came in and gave each of the children two goals to focus on. Our daughter was initially hesitant, but now takes showers regularly and it makes the whole house better.

My middle son has all these services, a feeding, occupational, speech, physical and mental health therapist. It makes a big difference.

We know our youngest son will not end up in prison but can have a future with a job and a family. Now we are not worrying about getting to the next day, we are focusing on getting them to the next hurdle.

I'm also being trained by (PATH) Parent to Parent/Family Voices of CT to be a parent volunteer to support people who are still drifting in the ocean. I've also joined a CT Hacker Space board, and I am getting training to become the board president. Before, I would have never had the time or energy to do this.

One thing I would change in a heartbeat is being able to see our Care Coordinator in person and give her a big hug for all she has done for us. We only met once when she dropped off sensory items that were needed for my youngest son. It's not easy talking about these deep personal things on a Zoom screen. She really saved our son's life and our whole family!

Questions for the Care Coordinator:

What challenges did you encounter during COVID-19 and how have they been addressed?

One of the challenges that the family and I faced during COVID-19, was the unexpected amount of unavailable system workers to collaborate with to meet the family's needs. Persistence and using one of the Wraparound values of "Never give up" was a strength used to address concerns that the family encountered.

What opportunities presented themselves and how are you using them/how are they impacting your work?

The opportunity that has presented itself is that now most services have moved to a virtual system, which has allowed for more collaboration opportunities and team interactions and participation.