

FIGHTING THE GOOD FIGHT

When a single mother found support at one of the Family-to-Family Health Information Centers, she regained her resolve to tackle life's challenges for the sake of her family and her community.

"Children are always a blessing, and they've been a blessing," says Tiffany, mom to 13-year-old twins, Elijah and Emmanuel. "They teach me something every day, and I thank God for them," Tiffany states calmly, radiating warmth and strength.

Tiffany is a devoted single mother who aims to create the most enriching environment possible for her twins. When Elijah and Emmanuel were 10 months old, she noticed that they were not reaching their developmental milestones. Her pediatrician noticed this too but encouraged mom to give the twins more time. Trained as a special education teacher, she knew children developed differently, but she was concerned.

As the boys entered their toddler phase, Tiffany enrolled them into a preschool program she thought would be nurturing. Tiffany explains, "Their speech was delayed. There were other social behaviors that worried me. I couldn't help but wonder if they had autism spectrum disorder." Tiffany had the children evaluated by a specialist at the nearby university children's hospital. Though the specialist agreed that the boys had some delays, the boys were not diagnosed with autism.

By the time Elijah and Emmanuel entered kindergarten, Tiffany had taken a demotion from her federal job to have more time to support her boys. "I put to work the skills I had. I searched the internet to find programs that would assist them and then tried to be creative in teaching them," she explains. She was supplementing their classroom curriculum by providing what she called "Mommy Work": games, activities, established routines, and incentives that aimed to help them thrive. Her mother was by her side, supporting her and the boys. Each child had different challenges though both had delays to their speech. Elijah wouldn't eat anything that was cut because he felt the food was somehow broken. Emmanuel was reserved and would break down crying and literally retreat when he couldn't articulate his needs. "I didn't want them shunned. I wanted them to have a voice and be able to express what they needed," describes Tiffany.

During this time and into the primary school years, Tiffany and her boys experienced heavy loss and incredible stress. Tiffany's father passed away when her boys were only 10 days old. Then, two uncles died within months of each other. Her mother—who she describes as her best friend and greatest champion—was then diagnosed with cancer when the boys were 5 years old. Tiffany became her mother's full-time caregiver while also trying to attend to her little boys' needs. While





caring for her mother, Tiffany developed debilitating back and nerve pain. Her mother would die three years later when the boys were 8 years old. The boys couldn't comprehend death. They kept asking Tiffany when their grandma would come back home. In these years, Tiffany struggled physically while dealing mentally with the stress of caring for children with differing medical conditions.

By the time Tiffany encountered the [Ohio Family-to-Family \(F2F\) Health Information Center](#), the twins were 11 years old. She explains, **"I was at my wit's end. I had advocated and advocated.** I had been back to that same university hospital when the boys were 8 years old. That second time I went, within 20 minutes, the doctors were telling me the boys had autism spectrum disorder. **I had gone**

5 years without a correct diagnosis. Five years without being able to get the appropriate help in place. And it was three more years of challenging times with schools and medical providers before I finally found the F2F center." She continued, "I needed additional help because of my own disability and lack of mobility. I was beyond exhausted."

"This peer support became my lifeline."

- Tiffany, mom of twin boys with autism

From the moment Tiffany connected with the F2F Health Information Center, she received the support that she sorely needed. She said, "It was nice to finally talk to someone who understood what I was going through. I also thought, 'Oh no! Not another fight.' But this peer support became my lifeline. I fought to fight the good fight—that my kids are worthy of the cause. And she held my hand and gave me that extra push I needed to keep moving forward to both secure the resources we needed and forge new opportunities for the boys' continued growth."

Through the F2F peer support specialist, Tiffany learned about programs that were responsive to her needs as well as the management of her sons' impairments. The peer specialist pointed her in the direction of webinars and teleconferences where she could learn about service integration in her community. She found a program geared toward helping children transition to adulthood. Tiffany reflects, **"I thought I was pretty-well educated, and yet she repeatedly pointed me in new directions, each idea or referral offering a positive step here and another positive step there."**

Through networking and shared experiences, **she not only gained valuable insights but also became a resource for others facing similar challenges.** "People perish because of a lack of knowledge," she notes, highlighting the importance of education and advocacy in creating better health and social outcomes for children and families. Tiffany describes, "We had a pool of people, coming together, networking, and serving each other." Tiffany now takes pride in helping others. She says, "People as far away as North Carolina have contacted me. Though our state systems might not be the same, processes often are similar, and I can direct them to where they might find solutions."

Tiffany speaks of the complexity in responding to individual family needs, saying, "Sometimes kids have comorbidities, and you have to think outside the box—look in another direction. When the school system isn't working for you, sometimes you can ask your doctor for referrals that helps another part of the system respond to a need we have."

F2F Health Information Centers

are keenly aware that resources for children with special health care needs are disparate, fragmented, and often unknown by those who unexpectedly need to access them.

When Elijah received a new diagnosis with features of Tourette syndrome, and exhibited new behaviors like hair pulling, Tiffany was grateful that her peer specialist continued to hold her hand through these emerging challenges. She is used to facing obstacles head on, but says, “Having her encouragement means I feel able to keep advocating for my boys *just one more time*. And there is always that one more time – whether it’s an issue with an educational plan at the school or in the clinical settings or with medical bill reimbursements.”

In the face of adversity, Tiffany’s devotion to Elijah and Emmanuel is steadfast. Despite misdiagnoses, personal loss, and her own physical challenges, she remains resilient. With support from the Family-to-Family Health Information Center, Tiffany continues to find vital assistance that not only makes her more effective for her sons’ journey, but also enables her to be of services to others. Her greatest lesson to date? She responds, “**There’s always purpose in your pain. It’s not about you, but who you can help along the way!**”



Quick Facts about F2F Health Information Centers

- Centers are in all 50 states, Washington, D.C., 5 territories, and 3 Tribal regions.
- Congress must reauthorize this program in FY 2024 for the program to continue.
- Each center currently receives funding ranging from the low to mid \$90,000s annually.
- Services are tailored to the unique needs for a child and their family.
- Centers also support the medical and public health professionals who serve children with special health care needs.
- Centers served **204,548 families** and **103,675 professionals** in 2022. A survey of parents’ experience show¹:

95%

of families surveyed said the information they received from their F2F would help their child.

97%

of families surveyed said they would recommend their F2F to others.

96%

of professionals surveyed said their F2F met their needs.

99%

of professionals surveyed said they would recommend their F2F to others.

¹ Family Voices Leadership in Family and Professional Partnerships, 2022 Data Brief.