CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS
FAMILY-TO-FAMILY (F2F) HEALTH INFORMATION CENTERS

A FAMILY'S JOURNEY

One family's journey to provide an accessible world to their child with special health care needs.

> "Being a first-time parent can be overwhelming. Being a first-time parent of a child with a disability is isolating…F2F made us feel less alone and let us know we had someone we could rely on for guidance."
> -Ben, father of Claire

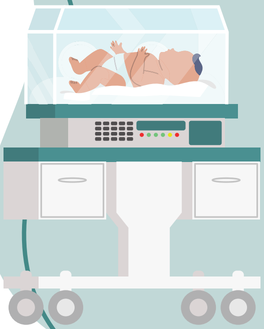
Ben and Suzie were excited to be expecting a baby girl in 2018. Like most parents, they thought they had some idea of how life would change. But little did they know just how much their world would change and how essential their Family-to-Family (F2F) Health Information Center support would prove.

Without any warning, baby Claire was born with a tumor compressing her spine. Though a surgeon would remove the tumor in the weeks after birth, the tumor had caused paralysis from her waist down. The family would be faced with Claire's medical complexities from paraplegia to scoliosis, to a neurogenic bladder, to a neurogenic colon, to chronic pain, to medical trauma, and, most recently, to a diagnosis of celiac disease, the root cause of numerous broken bones.

Each of these—many connected to the tumor, though not all—required the family to navigate a slew of medical treatments and the frustrating procedures of insurance approvals. They had to learn how to help Claire cope and how to administer ongoing care. They had to educate themselves and caregivers on safety and best practices for Claire, and even modify their home.

"Being a first-time parent can be overwhelming. Being the parent of a child with a disability is isolating," explained Ben. At a moment when Claire's parents desperately needed to lean on their social support system, their friends and family were not experienced nor equipped to help. The circumstances created extreme stress as Ben and Suzie worked to reorganize their lives, mentally and physically, for Claire. Ben noted, "Beyond maintaining day jobs and caring for Claire, Suzie and I were just surviving."

About 1 in 5 children have a special health care need. Of those, about 5-10% have medical complexity, meaning multiple and often interrelated medical issues.



Any child—at any time—could become a child with a special health care need—from illness, disease, or accident.

For more information about how MCHB and our partners can improve the lives for children and youth with special health care needs, visit **The Blueprint for Change**.

And so began an ever-evolving journey that is always about "what's next." Initial questions about medications, medical supplies, and palliative care then gave way to those about Medicaid, financing, retrofitting their home, and finding accessible schools.

Ben reached out to his Ohio state F2F Health Information Center when Claire was 4 years old. Amy became his peer support specialist.

Amy is both "one of a kind" and "one of many" who work at the F2F Health Information Centers across the country. These centers educate parents and connect them to resources so that parents can be knowledgeable advocates for their child.

F2F Health Information Centers are staffed by people who themselves have or have had children with special health care needs. They understand the unique challenges faced by children and families with complex health needs, and how those needs can change as the child grows.

"There is always the next thing," said Ben. "The next appointment or surgery. Doing triage. Routine appointments. Broken bones. There is anxiety, continual anxiety of what is next and where can we get help."

Staff at F2F Health Information Centers:

- Listen
- Empathize
- Educate
- Connect
- Care

"When I called, Amy listened. She continues to empathize, educate, connect, and care for my family and me," Ben stated. "F2F and her help have been critical for us, opening up possibilities and uncovering solutions." Ben continued, **"I only wish I had met Amy sooner. When I felt lost and overwhelmed, Amy showed me a path forward."**

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.

During Ben's initial inquiry, Amy spent hours on the phone, getting to know Ben's family. She **listened** to Claire's needs and Ben's priorities for his daughter. She **empathized**. Ben felt unburdened from the perpetual demand to help others who are inexperienced with children with special health care needs understand the maze of complex issues he faced.

When the family needed to modify their home to ensure safety for Claire, Amy **educated** Ben on funding resources available for home modifications. She also helped him understand Medicaid waivers—how they can help, optimal timing to apply for one, and challenges along the way.

Amy's guidance was invaluable as Ben and Suzie navigated the school setting. She **connected** Ben to free legal resources so that he could understand his daughter's rights for a nursing aide, and she helped the family research which school districts might provide a more optimal environment.

When Ben overheard a staff member speak in a way that demonstrated she did not have a full grasp of how Claire's wheelchair is an extension of her body, Amy proof-read Ben's email to the school and provided links to training resources for Ben to share with staff. "By educating me, Amy helped me feel more confident in advocating for my daughter." Soon, the school was up-to-speed, and Ben's worries calmed.

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Amy's support and connections extended beyond health and education sectors to areas of life such as childcare, camps, and even travel. The family believes travel is one of the greatest educators but were overwhelmed by the thought of traveling with a wheelchair and medical care that needed to be administered on a rigid timeline. But with the help of F2F, their dream came true. Ben and Suzie successfully navigated a myriad of wheelchair, health, and medical supply logistics to travel with their extended family. Ben notes, "I think we're like all other parents in that we want our daughter to feel like anything is possible; that she can do hard things; that she can go places. We want her to feel she can travel wherever she wants. **When the world is accessible, anything is possible. F2F helped us create that accessibility for her.**"

Above all else, perhaps the most profound aspect of Amy's involvement has been her genuine **care**. Beyond being a supporter, she has become a sounding board for the family over the last 2 years, checking in frequently, offering support and encouragement. In the face of the challenges that life with a child with a disability can present, Amy has been a steady presence, a lifeline.

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, at a particular point in time, 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 show[1]:

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.

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

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Maternal & Child Health