

Insights

Getting My Son the Support He Needed Shouldn't Have Been this Hard



"The supports exist and can help children thrive," says NICHQ Director of Programs, Meghan Johnson, MSc. "We just need to build the connections that make these supports accessible to everyone."

When NICHQ's Director of Programs' second son was just six months old, she began to wonder if something might be wrong.

"Evan was late to some important early developmental milestones, like rolling over. We worried he was falling behind, especially a few months later when he didn't start to crawl," Meghan Johnson, MSc, explains. "As soon as I started wondering if something might be wrong, I started asking questions. As someone who works in maternal and child health, I know how important those early years are for child development; I knew I had to speak up."

Her pediatrician was at first reluctant to sound alarm bells. After all, Evan was still early in development and might catch up. But Meghan knew in her gut that something just wasn't right. Deciding to act, she self-referred Evan for [early intervention](#) services, which are state-run programs that helps babies and toddlers meet their developmental milestones. Based on an early intervention evaluation, Evan had developmental delays in multiple areas, which qualified

him to receive support.

“Finding out your child needs extra help is scary, but it’s a lot better than the alternative of being a worried parent and not knowing how to help your little one,” says Meghan. “Once Evan started receiving early intervention, he had therapists and other supports in place. We were *doing* something instead of just waiting and hoping.”

Evan started early intervention services when he was close to a year old. At 18 months, he still wasn’t walking and Meghan’s pediatrician, realizing Evan needed more support, suggested further developmental evaluation.

“This was the right next step for us,” says Meghan, “but the system didn’t make it easy.” Appointments were booked out eight to 12 months in advance. And the hospital wouldn’t even consider making the appointment until Meghan had completed a 20-page patient intake packet. At best, Evan would be lucky to receive a screening sometime after his second birthday. And this with a mother who had already been advocating for him for over a year.

“I just kept thinking, ‘I work in this system and I still can’t get my child the services he needs. What if I didn’t speak English? What if I didn’t have a supportive family network or workplace,’ recalls Meghan. “And then I would just get mad because it’s unacceptable that something this important is so hard.”

Meghan’s family was ultimately lucky. Their pediatrician advocated on their behalf so Evan could see a pediatric neurologist later that month. When Evan was 2, he graduated from early intervention having reached age-appropriate developmental milestones. Because of the support he received, Evan caught up.

“Not everyone gets that lucky though,” says Meghan. “The [early childhood system](#) is too complicated and many parents don’t have the resources or time to navigate it. I spent months advocating on Evan’s behalf, going to extra doctor appointments and doing research. Once Evan started early intervention, we had weekly visits and group therapy sessions. And the phone calls. So many phone calls with specialists as we tried to figure out our options. Eventually, I had to cut back my hours at work. If I had any other social determinant of health—lived in a remote area, had less flexibility with my schedule, less support from my family, you name it—Evan wouldn’t have been able to get the care he needed. And there wouldn’t have been anything I could do to change that.”

While Meghan’s experience is troubling, she is quick to point out that it also suggests the potential power in our systems.

“Early intervention was incredible and gave us so much support, and we saw first-hand how much influence a pediatrician can have as an advocate,” she says. “The supports exist and can help children thrive; we just need to build the connections that make these supports accessible to everyone.”

Interested in hearing more from NICHQ moms?

Enjoy this video about how their experiences as mothers inspire their work. Then, consider sharing a time when you've had to advocate on behalf of your child. Your experiences can help change future children's health outcomes. [Email us](#) to tell us your story.