

Stepping Stones and Our Family

“Hello, um...my name is Jennifer Blougouras. I just had a baby two weeks ago, and he has Down syndrome.”

This was the call I made to Stepping Stones on a bright, sunny morning in mid-April of 2005. I was a wreck. When I was thirty-seven weeks pregnant, we had discovered that our son, Nicholas, would have Down syndrome. On a routine ultrasound, the doctor noticed his legs were measuring short. This led us to get a more high-powered ultrasound. Which led them to discover a heart defect. Which led me to get an amnio. Which led to a very late diagnosis of Down syndrome. Prior to this, we had “passed” all the screening tests. And now, this life-changing diagnosis. Our world came crashing down. Life, as I knew it, was over. This was a fate worse than death. Or so I thought.

Still, there was a baby. A baby who would need things. A baby who would need me to keep it together. I didn’t have the luxury of falling apart.

“I know he’ll need something called Early Intervention,” I asked a geneticist at the hospital. “What is that and where do I find it.”

“Look it up in the Yellow Pages,” he said.

And then the phone calls began. I found myself in the Byzantine, confusing world of Special Needs. Words like “Service Coordinator,” and phrases like “IFSP” baffled me in my fragile state. Red tape and multiple phone calls filled my days. I was simply another case number. And no one called me back. I would leave beseeching messages, begging people to call me back so Nick could start services, all the while hating the fact that I even had to call these people in the first place.

I went on the NADS website message board. I posted a message: NEED HELP IN NORTHERN NEW JERSEY. I posted about what a difficult time I was having—both emotionally, and on a practical level, getting EI set up. A very kind woman in Sparta, NJ, gave me the name and number of Stepping Stones. I placed the call. I didn’t have much hope that I’d get a phone call back. I thought Stepping Stones would be another place I’d have to chase down and repeatedly call.

To my amazement, Judy Bellina, the Director of Early Intervention, called me back in five minutes. I was shocked. Someone cared. I was a priority to someone.

We made an appointment for my husband, son and me to visit the school in two weeks. “What should I be doing in the meantime? What kind of exercises, what kind of positions?” I asked Judy. I felt that time was slipping away, that I was losing crucial information about how to stimulate him, how to help him.

“His job right now is just to be a baby,” she said. “He’s just a baby.” Maybe Judy didn’t realize it at the time, but these words were the first thing that put me on the road to seeing Nick as Nick. Just a baby. Not a diagnosis. Not a thing that needed to be stimulated. Just a baby...

When we got to Stepping Stones two weeks later, Judy had us sit in on an Early Intervention class and I remember crying as I sat there, and trying to hide it. Yes, I was still sad that we had to be here in the first place, but there was something else to my tears. I looked around the room, at the mothers and fathers working with their babies; at the therapists giving information and demonstrating various techniques. A dad, cradling his little baby girl in pink. Two ten-month-olds, face-to-face, passing a rubber clown back and forth, while their mothers kneeled behind them. A solemn-faced mother with dark hair, tenderly removing the socks from the plump feet of her four month old. These were our people. Our people. We weren’t alone anymore. And that’s why I cried.

Today, Nick is a happy, healthy three-and-a-half year old who attends the pre-school at Stepping Stones full-time. So much has changed in our lives since that first phone call back in mid-April of 2005. But one thing that hasn’t changed is the fact that every time I walk through the doors of Stepping Stones, I think, “Our people.” And instead of crying, I smile.