

The reluctant Mom

You need to learn to live in both worlds. By the time Matthew was 18 months old, I was a master at living in the “typical” world. I had two older children, and was very clicked in to my community, my church, local mom’s group and all the little classes for babies. I was totally ok. More than ok.

Matthew was a wonderful, thriving, gorgeous boy who just happened to have Down syndrome. The PR machine that I had created was in full swing. I showered and dressed every day, hair and makeup perfect; outfits (my son’s and mine) perfectly ironed. In fact, I later described my iron as “my very best friend”. It was all about presenting my son to the world in the most positive way, and it really helped. It helped me, and helped those around me get comfortable with him. But as you can imagine, it wore thin.

Besides my husband, and the wonderful strangers in several chat rooms, there was no one around me who “got it”. I almost always cried alone. And those first two years there really was a lot to cry about. My son had a heart defect that needed surgery, and a thyroid condition, and had been hospitalized twice – once with bronchiolitis and once with pneumonia. And I spent countless hours trying to learn exactly how to be an expert at Down syndrome so that I would know if the NJ State therapists assigned to my child were doing it right.

Enter Stepping Stones.

I may very well have been the most reluctant mom there. I arrived and the reality was that although I was “really doing well”, I “really hadn’t processed” many of my feelings about having a child with Down syndrome. And I was pretty angry that I had to sit in a room and talk about those feelings.

But here’s where the story gets good. At Stepping Stones I learned to live in the “other” world too – the world of parents whose children have Down syndrome. And I have met the most amazing families, and lifelong friends in that world.

I learned that I didn’t have to become an expert on Down syndrome, because at Stepping Stones, the experts are right there. I could finally breathe a little, because I knew that my son was in good hands. Stepping Stones has a staff of highly experienced teachers and therapists, and a program that for more than thirty years has been helping families of babies and children with Down syndrome. I got to meet parents who lived close by, whose children were the same age as mine. Parents who knew doctors that were smart *and* compassionate. Parents who were able to navigate the transition from Early Intervention to Preschool. These people “got it”, and not only cried with me, but also shared my joy at each little miraculous triumph!

I learned so much about my child, and myself. Somewhere along my journey, I learned that my greatest challenge as a mother was to find a balance between my worlds, ***to learn to live in both worlds***. And I credit Stepping Stones with giving me the tools to do just that