

'Raising a child with special needs changed us for the better'

Life will never look the same again. But along with the heartache and struggle come amazing rewards

The birth of my son should have been the happiest time of my life; it turned into a living nightmare. Max had a stroke that left his brain damaged. The neurologist who broke the news said Max might never walk or talk, and he could have mental retardation as well as vision and hearing problems. My husband, Dave, put his head on the table, his shoulders heaving with sobs. I sat quietly, too numb to cry.

That was eight years ago, and I thought my life was over. A child with such severe special needs surely would have a miserable existence. But then there was the reality of Max, who had the most yummy-pudgy

hands and gigantic smile. The delays came, along with a diagnosis of cerebral palsy—and some serious determination. Max crawled at 2, walked at 3 and rode a special tricycle at 5. No sound was sweeter than the day he called me “Ohmmmy” at age 6. Today, speech is a challenge, and he has cognitive delays and trouble using his hands. But, wow, has he proved the doomsaying doctors—and me—wrong.

Max opened up a whole new world for me. He has taught me to savor life's little joys—whether it's coffee out with my husband, pruning the vegetable garden or swinging my kids in the yard. I'm an editor and writer by trade, and two years ago I started a blog, Love That Max, to inspire parents of kids with disabilities, trade notes, cheer on our kids and laugh together. We face challenges, but we have good lives, ones enriched by our kids. I've met a lot of mothers who feel just like me and the women on these pages. They don't think they have kids with special needs—they realize they have ones with special powers.

By Ellen Seidman



The author and Max



KECIA COX, 32, MURRAY, UTAH; MOM TO BREE, 4
'My little girl showed me what perfect really means'

When Bree was born, I hung a framed quote over the garage that says, “Life doesn't have to be perfect to be wonderful.” In those days, I needed to remember that. Before Bree, I had two beautiful girls, a devoted husband, a nice home—I'd always been on top of everything, and I liked it that way. After Bree was born, I thought my perfect world was gone. Instead, she taught me that my idea of perfect was all wrong.

Bree was just a few hours old when our doctor told Kris

Down syndrome said to me, “Put the development books away and enjoy your baby. She'll do things at different times and in different ways, but she'll do them.” My friend was right. Bree walked at 2, earlier than I expected. Other things came more slowly, but we all appreciate her hard-won achievements so much—like the time she drew a line on paper or drank from a glass without dumping the contents down her cheek.

It makes my heart ache when people can't see Bree as I do. It was hard to have her scored against a “typical” child when we had her evaluated before preschool. It also has been frustrating when friends and family relate everything about her to her condition. If Bree cries, they ask, “Is that typical of a child with Down's?” I say, “No, it's typical of a little kid!” Kris even had to speak up to a bunch of guys he was golfing with the other day, when they used the word *retard*. I was so proud of him for that.

and me that she had Down syndrome. A nurse who had a child with special needs cried with us. “It's the greatest blessing you'll ever have,” she said, “though you may not realize it now.”

Growing up, I didn't know anyone who had disabilities, and trying to imagine being a mom to a child of special needs scared me, frankly. That first year, I was overwhelmed by anxiety and doctor appointments. Although Bree was relatively healthy, she had weak muscle tone and fine-motor-skill issues; even sitting up was hard for her. I tortured myself reading and fretting about when Bree would hit certain milestones.

Then one day, a good friend who has an 18-year-old with

The world would have us believe that being different means you are somehow not perfect. But I have learned that by regarding Bree as “differently abled” rather than disabled, I can really see all that she has to give. My life may not look like what I once considered to be perfect, but it is often better.

Watching Bree grow and learn reminds me of something I once read about bumblebees. Myth has it that, according to the laws of aerodynamics, they shouldn't be able to fly. But the bumblebee doesn't know that—it just flies. Like the bumblebee, Bree doesn't know she is not “supposed” to fly. But she does.



These days, Kecia forgoes a perfectly ordered house in favor of magical moments with Bree. Inset: Bree and Kecia with, from left, Adrie, 6, Kris, 34, and Kyra, 8.

FROM LEFT, NO CREDIT, DAN CAMPBELL

DAN CAMPBELL

We came through

Did you know?

According to the U.S. Department of Health and Human Services, more than a fifth of households with children have at least one child with special health-care needs.

Debbie with Addison, her "princess." Below: Debbie and Addison with Noah, 6, and Shawn, 37.

DEBBIE SMITH, 34, LILBURN, GA.; MOM TO ADDISON, 4

'My daughter taught me patience—and empathy'

Before I had kids, I didn't have much compassion for mothers. I'd see a child having a meltdown and wonder what was wrong with that mom and why she couldn't control her child. Then I had a little girl with a rare disorder, and suddenly I was the mom everyone stared at.

I had a totally normal pregnancy that ended in a C-section. "Is it a boy or a girl?" I kept asking from the operating table, but there was silence as they worked on my baby. They whisked her off to the neonatal intensive-care unit, and my husband, Shawn, went up with them. I lay in the recovery room alone, crying and crying.

I was told what was wrong with my child before I ever laid eyes on her: Her head was misshapen, her ears were set too low, her face was crooked and she wasn't holding her hands or feet correctly. Looking back, it makes me so angry that the first time I saw Addison, I wasn't looking at the sweet baby I had carried for nine months. I wasn't looking at her beautiful red hair. I was looking at the shape of her head, the look of her ears, the movement of her hands and feet.

It took three weeks to discover that

Addison had Trisomy 9, a chromosomal disorder that's so unusual, her doctors couldn't tell us what to expect. All my dreams for Addison were gone. I had to learn to savor each day.

The first year was tough. When Addison was 10 days old, her doctors put in a feeding tube because she lacked the coordination to suck, swallow or breathe. Every



day was exhausting. At night I'd put splints on her hands and feet to position them right, give her several medications and make sure her oxygen tank and monitor were working properly.

Whenever we went out, people couldn't

stop staring, even at church. Once a cashier asked, "What is wrong with your baby?" I was furious.

But Addison is coming along at her own pace. At 18 months she was off the oxygen at night, and in 2009 she learned to get around using a walker. Her personality has blossomed, and she has the biggest smile—anyone who spends time with her just falls in love. She's babbling a lot now. We hope that words will come and that eventually she'll be able to eat on her own.

Seeing Addison follow her own time line has given me so much more patience with her progress and in my own life. It certainly made me a better elementary-school teacher. I saw each student's unique gifts and challenges with more clarity, and I am more empathetic.

The stares still bother me. I wish I could go to Target or anywhere and just be a normal mom. I tend to act overly happy, trying to avoid the pity looks. But there are understanding people, too, like the lady at a pirate-and-princess party we attended who gave Addison a tiara, saying, "You are the prettiest princess here."

Now when I see a screaming child in the grocery store, I offer the mom a smile.

AMANDA KORNFIELD, 41, ROCKVILLE, MD.; MOM TO SAM-HENRY, 8

'My son made me less selfish'

Growing up, I was the baby in my family, and my parents spoiled me. They paid for college and afterward covered my rent and expenses while I worked entry-level jobs at TV stations. For years, I just wanted to go out with friends. I thought kids would be too much of a burden. But then I married Tom, the most wonderful man on the planet, and I decided I wanted a child just like him.

Sam-Henry was a hard baby. He wasn't responsive, he barely ate and he cried all the time. I felt so guilty—I thought I was doing something wrong. By age 2, he still couldn't sit and play with toys, he wasn't talking, he didn't even cuddle. Being with him was emotionally exhausting. I'd say things like, "I like him best when he's sleeping." People must have thought I was horrible.

When Sam-Henry was diagnosed with high-functioning autism, I wasn't sure I could handle a kid like him. When I went out with friends it just made me sad to hear them glow about their kids, because I couldn't relate at all. But in gathering a team of professionals to help him—a pediatrician, a behaviorist and two therapists—I began to discover a different reality. These amazing people saw such joy and possibility in Sam-Henry, and they helped me see it.

My son needed me. I stopped mourning the loss of my old, free-spirited self and became completely devoted to helping him. Not long after, Sam-Henry came down with a 102-degree fever right before Tom and I were to leave for our anniversary getaway. Instead of feeling robbed, I felt good being

the mama bear and staying home to take care of him.

Sam-Henry can communicate only in simple phrases, like "I want ball." He has learned to say hello to his peers, but he prefers to be on his own. If you picture a bunch of kids playing soccer, he's the one walking the perimeter with his head down, picking up leaves. He doesn't get invited to birthday parties or playdates—which can be hard for both of us.

But his laugh is infectious. I love it when he's giggling to himself over a scenario in his head that only he can understand. Actually, I think he got that from me! When he says hi to Madeline, his sister, I light up. He'll usually kiss or say "I love you" only when prompted, so when I get a hug from him for no reason, I know he really means it.

I never could have imagined the joy Sam-Henry would bring me or how he would change my life. I've become a more giving person. I started counseling parents of kids newly diagnosed with developmental disabilities; talking them through their anxiety and grief helped me understand



Amanda and Sam-Henry in mid-tickle fest. Below: Sam-Henry and Amanda with Tom, 41, and Madeline, 4.



how far I've come. One year I even raked in \$1,600 for the Autism Speaks Walk, a three-mile event that raises funds for research. The girl I used to be would have slept in, rented a DVD and ordered Chinese instead of marching in the cold rain for a cause. Sam-Henry didn't just make me a better mom—he made me a better person.

Why moms of special-needs kids rock! Adapted from the author's blog, lovethatmax.com

- ✪ Because we never thought that "doing it all" would mean doing this much. But we do it all, and then some.
- ✪ Because we've discovered patience we never knew we had.
- ✪ Because we are willing to do something 10 times, 1,000 times if that's what it takes for our kids to learn something new.
- ✪ Because we have heard doctors tell us the worst, and we've refused to believe them.

- ✪ Because we have bad days and breakdowns and bawl fests, then we pick ourselves up and keep right on going.
- ✪ Because we manage to get ourselves together and out the door looking pretty damn good. Heck, we even make sweatpants look attractive.
- ✪ Because we are strong. Who knew we could be this strong?
- ✪ Because we aren't just moms, wives, cleaners, chauffeurs,

- cooks and women who work. We are also physical therapists, speech therapists, occupational therapists, teachers, nurses, researchers, coaches and cheerleaders.
- ✪ Because we give our kids endless love and still have so much love left for our other kids, our husbands, our family.
- ✪ Because we understand our kids better than anyone else does—even if they can't talk or

- gesture or look us in the eye. We know. We just know.
- ✪ Because we never stop pushing, or hoping, for our kids.
- ✪ Because just when it seems like things are going OK, they're suddenly not, but we deal. We deal even when it seems like our heads or hearts might explode.
- ✪ Because when we look at our kids we just see great kids. Not kids with cerebral palsy/autism/Down syndrome/whatever label.

GUY CRITTENDEN