

Joy comes in surprising form

"He can't talk!" the two little girls giggled to each other, pointing. My 3-year-old son stood in front of them, jabbering happily in his nonsensical jargon, giggling right along with them. One of the girls reached out a hand and tapped him on the back — "You can't talk!" she laughed.

My chest felt tight. I blinked away tears as I grabbed my little boy's hand and led him away from them. A confused look crossed his face briefly before he launched back into his cheerful gibberish, waving a hand in the air for emphasis.

It was the first time I had witnessed other children making fun of my son's differences. I'm afraid it won't be the last.

We discovered my son's rare chromosome disorder during my pregnancy, through amniocentesis. Four prior miscarriages had alerted us to a genetic mutation carried by my husband and me that would often cause pregnancy loss, and rarely, a child with abnormalities. Scott is that rare case.

"Developmental delay," the genetic counselor told me the day I got the call. "Mild to moderate mental retardation." I sobbed quietly into the phone as I tried to make sense of it, tried to understand the words he was saying applied to my baby. In that 10-minute phone call, I felt as though I had aged 10 years.

This is not my life, I found myself shouting in my head. Do you hear me? I am not that parent! This is not my life!

But it is my life, and I am that parent. For the past three and a half years, I have been that parent.

When Scott was born, I fell in love, and I fell hard. He was glorious, with a halo of white blond hair and a rosebud mouth. I couldn't help but wonder - maybe they were wrong. But time would prove otherwise. Scott was 18 months old before he crawled, 2 and a half years old before he walked. Now, at 3 and a half, Scott does not really talk.

It is hard, watching other children pass yours by. There is a certain grief involved, and it creeps up on you, again and again, as you come to terms with the path you are now on



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and the path you will never take with your child. Dreams of college graduations and wedding days and grandchildren vaporize and disappear, replaced with a future that is unknown and sometimes frightening. But mostly, there is joy. As I stood in the doorway of Scott's room last week and watched him stack blocks for the first time, my heart nearly burst with it. When my little boy wraps his arms around my neck, I am sometimes left breathless at the gift I have been given in my son.

Well-meaning friends and family have offered prayers of healing for Scott. But the truth is, I have been the one who needs healing, not him. Scott is exactly as he should be, and it is human weakness and lack of understanding that clouds his perfection. You might say we all need a little bit of healing, that we might be freed of our expectations of what makes a valuable or successful life, that we might see Scott - and others like him - as the miracle he is instead of grieving what he will never be.

My parenting journey is different than I thought it would be. It is harder. There are more opportunities for hurt and pain, and I want to protect my little boy from all of it. But I keep reminding myself - for every child who laughs at Scott's inability to talk, there is a child who invites him to play. There are children who share with him their toys and offer a hand to him when he falls down. There are teachers and therapists who celebrate when he scribbles on a piece of paper or when he kicks a ball.

The grief, it comes and goes, and I imagine it always will. No matter how settled I am in this life we have, it will always hurt to see Scott struggle to do things that come easily to other children his age. But I can't stay in that place for long - the pain would consume me if I let it.

So I focus on today, on what Scott can do and how far he has come. I gather him into my lap and tickle him just to hear him laugh.

No, it's not the path I imagined for my family, but it's a path with blessings at the end and along the way. Mostly, there is joy.