

# **Voices: Helpful ministry to special-needs families**

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The church knows we need to be sensitive to special needs and open to special-needs ministry, but we don't know how. We tend to be scared to touch it, because we don't want to say or do the wrong thing.

I wasn't that different. During more than 10 years in kids' ministry, I tried to be accommodating to kids with special needs. However, I didn't do anything to reach out to and love on those kids and their parents.

May 18, 2022—the day my son was born—did not go any way I expected. Most “birth” days don't if we're honest.

However, being told my son likely had Down syndrome just moments after he was born and then being swept away quickly to the neonatal intensive care unit for breathing and sugar issues was far from what I had imagined. We knew NICU was a possibility, but a Down syndrome diagnosis? No.

## **When things changed**

The year leading up to our son's birth was challenging. My depression was at its all-time worst. We had a move to Alaska from Texas on the horizon, and my pregnancy culminated in gestational hypertension and pre-eclampsia.

Hearing “Down syndrome” in the recovery room was shocking. The honest first thing we cried out was, “Why us, God?”

There was deep pain and questioning: “Did I cause this?”

No, I didn't. Down syndrome is a genetic deformation that occurs by happenstance at the moment of conception. You can read more about Down syndrome at the [National Down Syndrome Society website](#).

We worried: "I will likely have to bury my son."

Historically, people with Down syndrome have had shorter [life expectancies](#) than the average person.

## Mix of emotions

There was a wave of grief as the life I envisioned for my son quickly faded away. It was extremely humbling and heavy.

"You were handed an early preview of all the trials your child would face the day he was born. Most parents don't get that," my counselor said.

I battled grief, anger with God, guilt for being upset at the diagnosis, worry about what was happening in the NICU. In the midst of this, we had to tell our family and worried friends who hadn't heard anything from us. We grieved right alongside being brave and becoming advocates.

Never had I felt such a swish-swash of emotions: moments of great joy together with deep grief, moments of gratitude for our beautiful full-of-life son and also anger and questioning, moments feeling angry God "chose" me and also deeply humbled and honored that God *chose* me.

I struggled with feeling all those things, particularly the negative things, but I finally came to a place where it's OK to feel all of it.

## Still processing

Eight months later, I still go back-and-forth. I grieve when I see my friends'

kids who were born around the same time reach milestones my son hasn't or is far from reaching.

I grieve when I see others putting together nurseries and taking newborn pictures in their homes—things we didn't get to do due to moving and then a NICU stay, things we dreamed of doing that felt taken away.

I know these things are superficial, of this earth and shouldn't bother me, but they do. It's very much a part of the grieving process, something I am sure I will navigate on and off for the rest of my life.

## **Actions that help**

We are so blessed to have such a great family, friends and church family who supported us during this time.

With a child in the NICU, we couldn't be swarmed with people. Just getting family in the NICU to see our son maxed out our visitor limit.

After I was discharged but our son was still there, we spent our time going back-and-forth to the hospital. When we weren't at the hospital, we were home sleeping.

People who gave us gas money, gift cards for quick meals, or accommodated our schedule to have dinner with us close to the hospital were the biggest blessings.

The people who didn't try to find the words, but just listened to us and let us process were so helpful. Those who held us and supported us in our grief were so special. Those who connected us with other parents of Down syndrome kids or local and national resources were so helpful.

I am thankful for the Baylor Scott and White Hospital in downtown Dallas for delivering our baby and lovingly caring for all of us in those early days

of his life.

## Special needs ministry

Ministering to parents of special needs is a necessity in the church. Ministering to each family will be different. We are one of thousands of stories. There is so much involved I never knew or understood. I hope and pray I can continue to shed light on the ways the church can minister to this special population.

To get a glimpse into what it is like, we can start by educating ourselves on what special needs is and isn't. Then, we can walk alongside families with special needs. For some, they know before the baby is born; others learn at birth. Either way it is equally challenging.

Learning your child has special needs can be a crisis of faith, a deep moment of questioning, and if still pregnant, a reason some consider terminating the pregnancy. This is where the church can step in to be a support, a resource, a refuge and a place of hope.

If you have specific questions about how to minister to or support families with special needs, I would be happy to help.

*Ashley Myers is a wife, special needs mom and former children's minister. She has a deep love of Texas Baptists, the church and helping families experience faith at home. She and her family now live in Alaska. You can follow their journey and the upcoming launch of her new ministry, The Abiding Family, on [Facebook](#) and [Instagram: @the.abiding.family](#). The views expressed are those of the author.*