

Matt: Hi. I'm Matt

Jackie: I'm Jackie, and these are our daughters, Lydia and Carly.

Starting our family was a little dramatic, but not for the reasons you might think. Back in the summer of 2008, we were expecting our first child, and we were pretty certain it was a boy. Since we were about four weeks from our due date, we thought we better come up with a girl name, just in case our instincts were wrong.

Matt: And then a few hours later, Jackie's water broke.

After that, it was kind of a whirlwind. We rushed to the hospital and during an ultrasound, they found our baby's heartbeat was getting weaker. So they rushed her in for an emergency C-section.

By the time I was all gowned up, I got into the room just in time to see Lydia being born. She was little, just 5 lbs 4 oz. It was kind of wild for a first-time situation.

We all have movies and things you have in your mind of everybody being in the room together, and then baby gets placed with mom, dad slides into the picture... and yeah, it wasn't like that.

Soon after her birth, one of the nurses mentioned she had some markers for Down syndrome, but they weren't sure and wanted to wait on genetic testing.

Truly, the possibility of Down syndrome was far less pressing than my wife having just had a major, unplanned surgery. We just kind of pushed it aside.

JACKIE: Two days later, testing confirmed Lydia did have Down syndrome, which included a massive heart defect that need to be repaired very soon.

My mom had been a para for a boy with Down syndrome for a couple of years, so it wasn't really foreign to us.

I knew it was going to be an interesting turn in our lives, but honestly, I wasn't that scared. I didn't panic. No one crushed us with negative expectations for our child.

MATT: Soon after Lydia was born, we had a lot of good information about Down syndrome handed to us immediately.

We had early intervention services. A ton of information and resources. We didn't know it at the time, but we would soon learn that Denver was a research hub for all things Down syndrome and we were one of the first generations of families to be in the right place at the right time.

I've heard other parents of kids with Down syndrome talk about horrible ways doctors delivered their child's diagnosis. Not the case for us.

We know that most parents of kids with disabilities really struggle with fear and uncertainty, and that wasn't true for us either.

Sure, we hadn't imagined having a child with Down syndrome, but we knew it wasn't the end of the world.

*We're the after story.*

We're the positive story that came from generations of work by groups like The Arc who fought for our daughter's place in the community.

But being the after story doesn't mean we don't still need and value The Arc.

Jackie: For the first 15 months of Lydia's life, we were on auto-pilot. We were doing what we were told to do.

Getting her ready for and through heart surgery. The worst day of my life wasn't the day I was told she had Down syndrome, it was the day I had to hand my tiny baby over for surgery. Once the surgery was behind us and her medical issues were stabilized, we finally had the chance to do something for ourselves as parents. The Mobilizing Families training at The Arc was one of the first things we did that we got to choose, that would help us to be better parents and advocates for Lydia.

Matt: Mobilizing Families was a great starting point for us. From that moment on, The Arc has been a big part of our lives. It's somewhere we can go with any question and get good information and resources, about anything. It's really the only place where you go where everyone is experiencing something disability-related, and you're all just in it together, supporting each other.

Jackie: The Arc makes me feel like I've got a small army behind me. If you're having a time where you feel alone in something, you don't have to. You can reach out to The Arc. It's a comforting thing as a parent to know The Arc is there for whatever comes your way.

Now that we're a little further down the road, we've come back as presenters at Mobilizing Families, and it's been great to share our story – Lydia's story -- with other parents. We get to let other parents see that it won't always be auto-pilot, that they will be living and thriving and enjoying it.

We show other parents that life goes on, and that there are some really cool moments that come from having a child with special needs.

Matt: We also come to all of The Arc's community events, like the picnic and the holiday party, this luncheon, the 5K.

It's a fun community to be around. You always feel that people are genuinely welcoming. You see familiar people. There's a really strong sense of love and support. And our kids love it.

Jackie: You've heard it from other stories today, but it's true. The Arc is part of our family, too.

Thank you.