

Down Syndrome: Enjoying Life at a Different Pace

A Kansas mother shares her experiences of raising a child with an extra chromosome

By Amy Torkelson, Communications Director, Kansans for Life

Matt and Pauline Shibley live in Wichita, Kansas, with their five children. Matt is a carpenter and Pauline, formally a teacher, is currently staying home with the children. Pauline has generously taken time out of her busy life to participate in an interview so that others may have a glimpse of what it is like to raise a child with special needs.

Q. What were your initial fears when you found out your child had Down syndrome?

A. We were worried we wouldn't be good enough parents. We were scared that people would not treat Leo the same as they treat our other children. We were also afraid Leo's siblings would be embarrassed or unhappy about it. A doctor gave us a book about the health risks associated with Down syndrome and that made us really worried — a higher risk of leukemia, thyroid problems, heart problems, lots of things. I read the entire book but then I threw the book away! I did not want to spend my life worrying that every little thing was cancer or something. I felt like I just needed to find a good doctor and let the doctor take care of the medical worries.

Q. How do you feel now about having a child with Down syndrome?

A. We don't worry anymore about what other people think. Leo's smiles and social charm have always made up for his lack of words. We hope his charm can keep him going even when he's too old to be "cute" anymore.

Sometimes the other kids get embarrassed when Leo doesn't understand the need to be quiet in certain situations.

Q. What information would you like to share with other parents who have just received a diagnosis of Down syndrome for their child?

A. There is a really good poem called, "Welcome to Holland" that was given to me when Leo was a baby, and I have it with my photographs. It helped me see that even though this is a different journey than we had expected, it is still a good journey.

I would also reassure new parents that I have been amazed at how Leo is much more like his typically-developing peers than he is different from them. He is progressing; he learns new skills; it just takes him longer than it took my other children to master the same skills. When Leo was a toddler he loved "Music Together" classes and he started singing the songs before he could talk. Now that he is six, he has played on a regular basketball team and a regular T-ball team and he did fine. You could not tell the difference between him and the other six-year-olds.

Q. What have you learned from being the parent of a child with special needs?

A. I have learned not to take anything for granted. When Leo learned how to say "Mom" or how to catch a ball, it was a really big deal. I have also learned that I have to be his voice, even if it makes me uncomfortable. He has no one to advocate for his rights except for me and Matt. He has a right to be included with typically-developing peers because he needs to see typical behavior and hear typical speech. He needs to be included with typical peers because that's how he can keep learning and developing.



Matt and Pauline Shibley with newborn Leo, 2010.

Q. Is your child with Down syndrome more difficult to parent than your typically-developing children?

A. No. Every child has a unique set of challenges. I don't feel like Leo's set of challenges weighs any heavier than my other four children.

Sure, Leo has needed more appointments, like speech therapy and occupational therapy. He needs to be supervised the way I would supervise a two-year-old even though he is six. But each of our children has his own unique needs and different demands on us at different stages of life.

The scariest things to deal with as a parent are *not* the kinds of things that can be found in a prenatal screening. Teens with drug or alcohol problems — just to give one example — are a much scarier thing to deal with as a parent than something like Down syndrome.

Q. What have Leo's siblings learned from having a brother with special needs?

A. We didn't even tell them at first that Leo had Down syndrome. We just wanted to introduce the kids to Leo as Leo, their little brother. As things went along I explained that we will have some extra work to do as a family because he has some challenges that mean it will take him longer to learn to do things.

We went to the Buddy Walk for the Down Syndrome Society of Wichita for the first time when Leo was seven months old. It was the first time we had been at an event where people with Down syndrome were gathered. Emma was three years old and said, "Mommy! Everyone here smiles like Leo!" We thought that was a good way to describe people who have Down syndrome., "Mom, there's a boy in my class who smiles like Leo," or "Look, there's a teenager who smiles like Leo."

The kids have learned that "fair" doesn't mean everyone gets the same thing. It means everyone gets what they need. Everyone needs different things. It makes the

other kids mad sometimes that Leo does not get in trouble for some of the things they did at the same age. Leo is six years old now but can't be expected to have the same behavior that a typically-developing six-year-old would have. If someone had told me when he was born, "Your son will have no concept of danger," that would about sum it up! Leo does need to be watched more closely than a typical six-year-old.

Leo's siblings have learned to be patient. They also learned sign language because Leo was delayed in learning to speak. Emma, who is three years older than Leo, helped a lot in teaching him to walk and is also the best at sign language. His older sister, Bella, has had to be especially patient with Leo as he often wants Bella, and no one but Bella, to do things for him. She has learned much selflessness from having Leo as a brother.

The siblings' favorite thing about Leo is his empathy. He can tell when

people are upset and will give a hug, go sit with the person, etc. Our family loves the saying, "The 21st chromosome is the love chromosome!"



Leo, age six, enjoys a pony ride at the September 2016 church picnic.

Preferred Language Guide

From the National Down Syndrome Society

People with Down syndrome should always be referred to as people first. Instead of "a Down syndrome child," it should be "a child with Down syndrome."

Down syndrome is a condition or a syndrome, not a disease.

People "have" Down syndrome; they do not "suffer from" it and are not "afflicted by" it.

"Typically developing" or "typical" is preferred over "normal."

"Intellectual disability" or "cognitive disability" has replaced "mental retardation" as the appropriate term.

NDSS strongly condemns the use of the word "retarded" in any derogatory context. Using this word is hurtful and suggests that people with disabilities are not competent.



Leo at the “Buddy Walk” for the Down Syndrome Society of Wichita, 2012.



The Shibley Family, 2016: (back row) Pauline, Nathan (17), Matt. (Middle row) Bella (14), Dominic (11). (Front row) Emma (9), Leo (6).



Leo loves parties! In this photo he is waiting in line to hit the piñata at a birthday party.



The 21st chromosome is the love chromosome! — Shibley family favorite saying.



What could beat spending time with grandparents?



Leo enjoys a preschool field trip to the Pumpkin Patch.