

Down Syndrome: Celebrating Every Milestone

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

By Amy Torkelson, Communications Director, Kansans for Life

Jason and Melissa Anderson live in Lawrence, Kansas, with their three children, Harper (13), Hayden (10), and Banks (8). Jason is a pharmacist, and Melissa works part-time in the insurance industry. Melissa 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. Harper is our first child. I was 29 years old when she was born in April 2003. I had a normal pregnancy and we had no indication that she had DS prior to her birth. She was born at 41 weeks and was very healthy when she was born. It was about 24 hours after her birth that our doctor came in and told us that Harper might have Down syndrome.

Although I think every new mom has an immediate feeling that she wants to protect her children, after hearing that I felt that protective instinct times thousands. I wanted to protect her from anyone ever teasing her, from people treating her differently.

I did not want her to miss out on all of the things that typical children get to do. I thought about her schooling, about prom, about driving a car ... all sorts of thoughts flooded my mind.

But after a few days we took this sweet baby home and we realized that she is just like any other child — all she needs is love.

There was also the fear of the unknown when it came to her health, but we just surrounded ourselves with

a great hospital that guided us through all her health concerns.

Because Harper was our firstborn, everything we went through with her was “normal” to us. We didn’t know any different. She sat up at six months but didn’t walk until 22 months.

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

A. Jason and I have the attitude that Harper is just like any other child. She is going to do all the things that any other child does. We/she may take a longer route to get there but she will do all the things that her peers do. It is our job to make sure she has all the right people and tools in her life to help her be successful.

We have always told everyone who has worked with Harper that we expect her to do anything that a peer might do and it is our job to get the tools for her to accomplish her goals. Harper is one of the hardest workers I know. She has been in physical therapy, occupational therapy, and speech therapy since she was four months

old and continues to do all of those. She is constantly working on goals and surpassing them.

Harper is 13 now and attends weekly dance classes, was in the school musical last year, and got a first place in her first swim meet over the summer. She is like her peers in that she is on her phone and i-pad way too much! She loves to hang out with her friends.



Melissa and Harper



Jason and one-year-old Harper



Harper was very excited on her first day of 8th grade at West Middle School, August 2016.

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

A. First of all I would say congratulations! I would say take a deep breath and just love your child. You will figure it all out. Your child will teach

you more than any book or school could ever teach you about life. She will teach you how to be a better person, how to be patient, and how to appreciate every little accomplishment. I would also say, yes, your lives are going to look different, but surround yourselves with supportive family, good doctors, therapists and teachers.



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

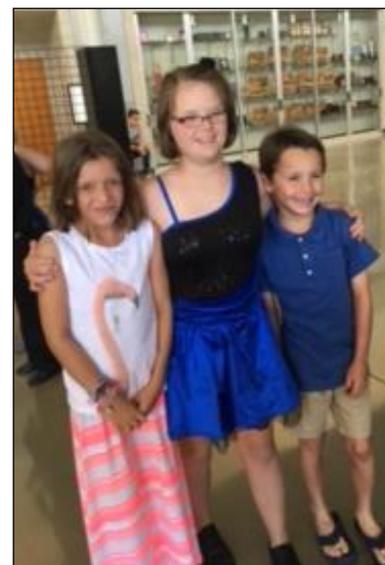
A. I have learned to celebrate every little milestone. I no longer take life so seriously; I have learned to slow down and not sweat the small stuff. Harper has never said an unkind word about anyone. She shows everyone love and friendship and is a little ray of sunshine that God has given to us.

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

A. I wouldn't say so. I think every child has ups and downs in their lives and at times are harder to parent than at other times. Many of Harper's needs and concerns are different than her siblings but not any harder.

Q. What have Harper's siblings learned from having a sister with special needs?

A. Hayden and Banks have learned so much from Harper! They are great teachers to her; they are great helpers when she needs it but they are also great examples to her when it comes to being independent. In the end, she is just their sister; she is not their sister with DS; she is just Harper.



Hayden, Harper, and Banks after Harper's dance recital.

A Child's Right to a Free and Appropriate Education

A summary of an article by the National Down Syndrome Society; see complete article at ndss.org

Federal laws protect the rights of children with disabilities, including children with Down syndrome, to receive a free, appropriate public education. Students receive special education and related services that meet their unique needs and prepare them for independent living, employment, or postsecondary education once their secondary education is complete.

Related services include transportation, speech-language pathology, audiology, interpreting services, psychological services, physical and occupational therapy, therapeutic recreation, social work services, school nurse services, counseling, orientation and mobility — whichever of these services are needed by the child in order for the child to benefit from special education services.

The "least restrictive environment" provision in the law means that preference is given to including a child in general classes as much as possible, and placing him in a special education classroom only when he is unable to benefit from the general instruction in the regular classroom. This insures that a child with a disability spends as much time as possible with non-disabled peers.

Of course, parents always have the right to place their child in a private school or home-school their child; these environments fall outside the scope of the "least restrictive environment" laws.



Harper played the role of a villager in her school play (photo with her parents, Melissa and Jason).



Harper loves to hang out with her friends.



Harper and Banks at a Royals game in August 2016. Harper's favorite thing about a Royals game is seeing Alex Gordon!



Harper with her friend, Cade, at the Step Up Walk in 2015.



Harper loves to spend time in the water. She has been swimming since she was six months old and now swims on a Special Olympics swim team.



Aunt Cece and Harper love to watch *The Voice* and go shopping together.



Harper poses for a photo with her grandparents after her dance recital.