

FINfacts



A publication of the Family Information Network of Ohio
for families with young children in Help Me Grow.
Funded by the Ohio Department of Health.

Speaking without words: One family's story

By Shannon Miller

When Julie and Tom Vanderhoff's daughter, Katie, was diagnosed with pervasive development disorder – a mild form of autism – the diagnosis confirmed what Julie had already suspected.

“At two years of age, there was still no language,” says Vanderhoff. She says Katie was reluctant to make eye contact with others, wasn't involved with other children and liked to play alone. “Her playing was lining up cars in a row, or watching the same video several times. She was also doing some [hand] flapping and spinning,” continues Vanderhoff.

“A lot of people tried reassuring me saying [Katie] would probably be talking before long,” but, following her instincts, Vanderhoff pushed for further testing, first from the family's pediatrician.

Vanderhoff says talking about the experience of having a child with autism is sometimes difficult to put into words.

“At the time [of diagnosis], I'd go out and see other children talking, and I was a little depressed because I wanted a healthy child.” But, she says having the diagnosis has helped the family move forward and help their daughter in the best ways possible: through intervention and supportive schooling.

The family started occupational and speech therapies right away, and has seen a lot of progress with Katie, who is now five and attending preschool in Findlay.

Vanderhoff says proudly, “She even says ‘mama’ – and that kinda melts your heart! But she always said ‘dada!’”

A milestone for the Vanderhoff family occurred when Katie started ice skating through a program created just for children with special needs. This program, Gliding Stars, has enabled Katie to improve her sensory sensitivities. The Vanderhoffs were reluctant to participate



Julie, Tom, Tyler & Katie

at first because skaters had to wear protective gear such as a helmet and harness in addition to ice skates. “Katie does not like to wear hats, boots or anything restricting or tight,” explains Vanderhoff. At first,

Katie wasn't willing to wear the required gear. One of the program's coordinators, Cindy Bregel, encouraged the family: “Cindy told me that with consistent practice, Katie would eventually accept putting on the equipment, but that this could possibly take a few months,” Vanderhoff says.

Katie surprised everyone: “It only took her about two weeks and she was willing to wear all the equipment.” She was very excited to skate each week – so excited Vanderhoff says “I had to hold her back until the volunteers were ready to put her on the ice!”

Vanderhoff can't say enough good things about Gliding Stars. “The skating program is wonderful,” she says. “I advise it to anyone with a child with special needs.” Each child is paired with

a volunteer who helps them learn to skate.

The Vanderhoffs have an older son, Tyler, age eight, who has adjusted despite the challenges faced with having a sibling with autism. “He's protective of her,” says Vanderhoff. “He's not embarrassed or shy that she has autism. He tells people and he helps her out.”

Vanderhoff admits certain challenges to having a child with autism and how it changes the family dynamic.

“She only eats certain foods, and it's trying at certain times of the year, like when my husband is out of town for work or during the holidays,” admits Vanderhoff. There are things parents can do to help their child – and the rest of the family – cope with changes, something that's often difficult for children with autism.

“She has a favorite doll. If we have to go on a long trip in the car, or to a doctor visit, we try to take some of those things along. We take books or videos – her comfort things.”

If you're a parent of a child with autism, Vanderhoff suggests, “try to stick with your child, do the intervention and try to teach them as much as possible. I know sometimes it's difficult, but therapies and schooling are the best things for a child with autism.”

Vanderhoff suggests seeking the support of other parents of children with autism. She attends a local support group. “Other moms get together and discuss varying topics.” She says it's been helpful knowing there are other parents out there who face the same challenges.

Vanderhoff admits that she often wonders what the future holds for Katie. “It's a difficult thing to think about,” she says candidly. “But there's so much out

(Continued on page 4)

The Shape of My Heart

by Jennifer Patterson

For as long as I can remember, I've always been special. My heart has been shaped because of a very special brother. His name is Samuel and this is my story.

I've always been a helper. When I was very little I started helping my mother and father. I liked to help mom clean and cook dinner. I liked to help my dad take pictures and take care of our puppy Jake. Mom and Dad always let me join in whatever they were doing.

Then my brother Samuel was born. For the first year our house was just like everyone else's. Samuel learned to talk and crawl and we played together. I was only two years old.

When Samuel was almost two, he stopped talking. I tried to talk to him, and he would act like he was deaf. I didn't understand what was happening. But my heart still felt the same. I knew Mom

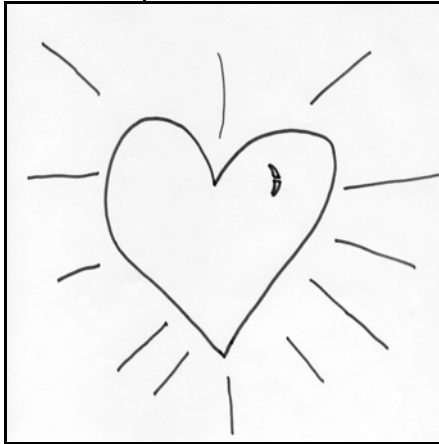
and Dad loved both of us, even though something was changing about Samuel.

I still played with Samuel and talked to Samuel. Now he didn't know who I was talking about. Mom and Dad started taking Samuel to doctors who didn't know what was happening to my brother. I always went to the doctors with my family. I played with the toys in the doctor's office while Mom and Dad talked to the doctors. One day the doctors said my brother had Autism. I didn't know what Autism was. I only knew who my brother was and liked him, most of the time.

I was going to preschool and I made a friend who was deaf. I really liked her. My teacher taught me to do sign language to talk to her. It was fun learning a new way to talk. We found a special school for Samuel, and my heart changed forever. Children at my brother's special school knew sign language too. Some of the kids were in wheelchairs and some

of them couldn't see. It was so much fun to go to pick my brother up at school. I got to help the children who needed help. They liked to play with me.

It never really bothered me if they could walk or see or hear. I would ask Samuel's teacher how to play and she would tell me. I learned a new way to talk and a new way to play. I got lots of practice playing with children who were special. I learned how to play with Samuel. I learned to understand what Samuel was trying to say, and it made me feel important.



Mom and Dad spent lots of time working with Samuel. Sometimes I felt like I was all alone because it took a lot of time to help Samuel understand things. I still knew that mom and dad loved me be-

cause sometimes they would come in to my room after they were done with Samuel and they would play "tickle torture" with me. That made me feel like I was not alone. I would lay on my bed and laugh with them. That felt good! I always liked when mom or dad would spend time with just me. We would do fun things without Samuel. Mom and I would go shopping and sometimes dad took me fishing.

Having a sibling with special needs can be good and bad. It's kind of like a newspaper with good and bad news. But in our house, there's more good news than bad.

The good news is he has taught me all about jungle animals, the order of the planets and he gets my mom to buy every Walt Disney video that comes out. When we took a trip to Disneyland, our family got a special pass to let us get into the rides without standing in line. We didn't have to wait for three hours like most people that went to Disneyland. We also

got to get into the shows without waiting.

But most of all, Samuel has shaped my heart by teaching me to be kind. I am able to be loving toward others because I have to be that way with Samuel. He has helped me learn to be understanding of how children need help and how it makes me feel when kids are judged by the way they look or talk. I like to meet other children with special needs because I can learn how people are different from me.

The bad news about having a brother like Samuel isn't because of him. The bad news is because of the way people treat him. I remember one time I was at a store and Samuel wanted to see the birds that were in the cages. He had a hard time waiting until we were ready to leave to see the birds. The clerk gave him a dirty look and my Mom asked her, "Is there a problem?" The clerk didn't understand that children with special needs don't always act like other kids.

I wish other people could understand and not judge Samuel. I felt very angry at the clerk because she was nasty and Samuel wasn't really hurting anything. My mom let him look at the birds even though the clerk gave us nasty looks.

If I had a magic wand I would wave it over the Earth and all of the people would understand about people who were different from them. Most people don't understand about people who are different from them. Most people don't understand disabilities until it happens in their family. People should take the time to learn about others and not just judge them by how they look.

People with disabilities have lots to teach us. Many of them are very smart and kind. I think people should just ask questions instead of staring. It makes me uncomfortable when people stare. A simple question like: "Why are you in a wheelchair?" or "why does Samuel do that?" is much better than just staring.

People with disabilities are just like you and me. Sometimes they're even smarter. Bill Gates, the man who made computers has been said to show signs of Autism.

(Continued on page 4)

Could these behaviors be autism?

Autism is characterized by careful consideration of a child's developmental progress in three areas of development: social interaction, communication, and restricted interests and/or other behavior patterns. When there are differences in the way a child's development is progressing in all three of these areas, Autism Spectrum Disorder (ASD) is a possible consideration.

Social Interaction:

In looking back on their child's development, parents will often say that something seemed different from early infancy through age three. For example, a child with social interaction differences may have not smiled back to adults or smiled less often than expected, not cuddled

much, made limited eye contact with others, not responded to their name being called and at times seemed to tune others out, even though hearing screenings are normal.

Parents typically may notice that their children may not follow a point when a parent points at an object and says "Look!" nor do they point for themselves toward an object they want. They may often pull a parent toward a desired item or simply try their best to get it for themselves.

Communication:

Many children with autism show significant language delays

or the use of their language may not have seemed like other children. Common communication difficulties for children with autism may include: talking very little, difficulty taking turns while communicating, hearing a child use a few words and then not hearing the words again for awhile, repeating words or phrases from TV or videos or the conversations of others, and most often having difficulty communicating even the basic of needs to adults such as food or drink requests.

Restricted Activities:

Restricted interests or other behavior differences in children with autism spectrum disorder are behaviors such as the use of fewer gestures or none at all (such as lack of pointing or pulling parents to wanted items, not waving good-bye, not reaching up to

parents to be held or playing pat-a-cake). Children with autism may be attached to specific objects to an excess, may be especially talented in putting objects like puzzles together, may sometimes repeat bodily actions (hand flapping, rocking, pacing, twirling), and may

not engage in pretend or make-believe play with dolls or stuffed animals. Because younger siblings of children already diagnosed with ASD have a higher risk for

Could it be autism?

What Parents Might Say About Behaviors/Restricted Activities

- "He plays with all of his toys by lining them up."
- "He studies things very carefully."
- "He plays by dumping his blocks and then putting them back again - over and over again...and over and over again."

- Warren, 2008

Could it be autism?

What Parents Might Say About Social Behaviors

- "It's hard to get his attention."
- "He seems to be in his own world."
- "Everything he does is on his own terms."
- "He completely ignores his baby sister."

But also...

- "He's very affectionate."
- "He loves to wrestle with his dad."

- Warren, 2008

also having ASD, parents and pediatricians are encouraged to carefully watch developmental milestones in social and communication skills. Screening tools that your pediatrician can perform, such as the *Modified Checklist for Autism in Toddlers (MCHAT)* may be used at well-baby checks. Specific red flags for a younger sibling (or any child): no bab-

Concerned? Follow your instincts... talk to your pediatrician.

Ohio Chapter American Academy of Pediatrics recommendations for developmental screening...

- At every Well Child Check: talk with parents about their concerns.
- 9 mo. Well Child Check—ASQ* or PEDS**
- 18 mo. Well Child Check - ASQ or PEDS / Autism screen (MCHAT)
- 30 (or 24) mo. Well Child Check - ASQ or PEDS / Autism screen (MCHAT)

bling by 12 months, no pointing or other gesturing by 12 months, no single words by 16 months, no 2-word phrases by 24 months old, or loss of any language or social skill at any age.

*ASQ - Ages & Stages Questionnaire
**PEDS - Parents' Evaluation of Developmental Status

Note: This information was taken from Understanding Autism Spectrum Disorders by American Academy of Pediatrics. To order a copy, go to www.aap.org/bookstore.

Could it be autism?

What Parents Might Say About Communication Behaviors

- "He gets things by himself."
- "He can't tell me what he wants."
- "He takes my hand and pulls me to whatever it is he wants."
- "He repeats lines and songs from TV and videos but doesn't use words to ask for things."

- Warren, 2008

Resources

www.autismspeaks.org

Autism Speaks is committed to raising public awareness about autism and its effects on individuals, families, and society. The site also has **First 100 Days Kit** - a tool kit to assist families in getting the critical information they need in the first 100 days after an autism diagnosis.

www.ianproject.org

IAN, the Interactive Autism Network, is an innovative online project designed to accelerate the pace of autism research by linking researchers and families.

www.firstsigns.org

First Signs is dedicated to educating parents and professionals about the early warning signs of autism and related disorders

www.cdc.gov/ncbddd/autism

has resources for families, educators, researchers...early warning signs of autism, information on screening, diagnosis, treatment, congressional activities and more.

www.ocali.org

Ohio Center for Autism and Low Incidence (OCALI) serves families, educators, and professionals working with students with autism and low-incidence disabilities, including autism spectrum disorders, multiple disabilities, orthopedic impairments, other health impairments, and traumatic brain injuries.

www.autismohio.org

The Autism Society of Ohio is a group of parents and professionals working on behalf of persons with autism and autism spectrum disorders (ASD) in the state of Ohio. The Autism Society of Ohio also acts as an information clearing house for persons with autism and ASD, their families, and the professionals who serve them in Ohio and neighboring states. Provides links to local chapters.

Books

Early Intervention & Autism: Real-Life Questions, Real-Life Answers
By James Ball

Ten Things Every Child With Autism Wishes You Knew
by Ellen Notbohm

(Continued from page 2)

Albert Einstein is another person who may have had Autism. Christopher Reeves who was Superman in all the movies is in a wheelchair. We have learned so much from all of these people. And Samuel has taught me many things. I think my heart has a shape that it wouldn't have had if I hadn't had Samuel for a brother. I found a way to get all of my emotions out by being creative. I dance and sing. I like to put on shows and draw. I also like to write poetry. When I'm dancing, I feel like I'm flying. I don't worry about anything else when I'm on the stage. I like to make people feel good when I dance and sing. I don't think I would be as good of a dancer if my heart was a different heart. I like to show the way I feel when I dance.

I know that because of the shape of my heart, I will be able to make my dreams of the future come true. I want to be a judge. Judges need to be fair, kind and understanding. I think my heart is the perfect shape to look at others and judge them fairly. I wouldn't judge them on the way they look or how much money they have because I have learned that all people are special. I know that others who are different from me can teach me many things.

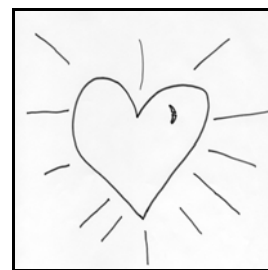
I would also like to be a pastor of a church. Having a brother with special needs has taught me to trust in God. I pray about learning to be kind and loving.

Another thing I might think about is becoming a teacher for children with special needs. I like working with children and helping them. I think my heart is big enough to love all the children.

I don't like having a brother with

special needs, I love it! Samuel has taught me lessons for life. He is the best brother in the world. My mom says that God sent him to us because He knew I would help him learn and love him. And because of the shape of my heart, I believe her!

Jennifer Patterson initially wrote "The Shape of My Heart" as a 5th grade student for a young authors project. Jennifer is currently a freshman at the University of Akron. She is majoring in Cultural Anthropology and intends to join the Peace Corps upon graduation. Her passion for equality has grown to include all the citizens of the world. She continues to believe her personal experience as a sibling of a person with a disability has been a blessing.



(Continued from page 1)

there that wasn't there before. Katie has improved so much with her new school and outside therapies," continues Vanderhoff. "Her eye contact has improved greatly, and she is starting to say some words like 'movie,' 'bubble,' 'more,' 'go,' and 'help.'" Vanderhoff says the family has used sign language to help Katie progress, and she is starting to learn how to dress herself. "We feel that with repetitive work, Katie's future should progress to new heights."

Talk to your service coordinator or family support specialist for information about local support groups or local recreational opportunities.

For information about Gliding Stars, please go to www.glidingstars.org