

One Woman's Journey Through Autism

Second in a Series

By Ashleigh Eisbrener

Her daughter was 15 months old. She was starting to walk, talk and play with her toys. She laughed, was affectionate and had friends. Mother, Kelly Weaver, loved watching her child grow and develop, but when Gillian started suddenly regressing Kelly became confused and scared. She was losing skills rapidly. She stopped pointing and waving, and she was different from the rest of the kids. Then she lost her speaking skills.

At age two, Gillian was diagnosed with autism, a developmental disorder that impairs social interaction and causes problems with verbal and nonverbal communication. Kelly's world turned upside down. "When she was diagnosed, I went and threw up a bunch of times then I laid on my bed and cried, kicked and screamed," she says. "Then literally, I got up and went to work."

Just 30 years ago autism was rare, occurring in five children per 10,000 live births. But since the early '90s, the rate of autism has increased exponentially. Some describe it as an epidemic. In 2007, the Center for Disease Control reported that one in 150 children is diagnosed with autism. The disorder has no single, known cause, but probable causes include genetic errors; environmental factors; and other concerns, such as labor, delivery and the immune system.

Those, like Kelly, who have children 10 or older are pioneers in autism. Unlike nowadays, where there is a wealth of organized, accurate information from books, Web sites and health professionals, eight years ago when Kelly searched the keyword "autism" on the internet, Web pages said her daughter's disorder was the result of her not being a loving and nurturing mother. These words motivated her to research deeper.

Kelly turned into a self-described warrior mom. "You learn everything you can," she says. "It's like learning a whole new life." She describes the diagnosis as a nightmare. She felt grief, anger and frustration. Her body went numb. For two years she researched nonstop, then a whole new wave of grief set in as she realized this was how her life would be. "You accept it many times along the way," she says.



This new lifestyle made Kelly fight to come to grips. "I felt like I was losing my child's childhood," she says. She started realizing her family wouldn't have the same preschool or kindergarten experiences as other families. She describes these overwhelming thoughts as a slippery slope that can lead to other unpleasant thoughts, such as "my child's never going to get married or live on her own...we're never going to be able to do Disney World...I'll never be a soccer mom." She'd become more upset when she talked to her friends with typical children. "Their bad day is that John didn't make the all star soccer team," Kelly says. "And I'm thinking, 'my kid can't even kick a ball.'" But she didn't let her thoughts take control of her actions.

Kelly set out to get Gillian a speech therapist, behavior consultants, special psychologists, attorneys to address the school system and more. "It becomes a life of its own," she says. It was a constant test. She tried things, and if they

didn't work, she'd change course and try something else. "You assemble the best team that you can and you figure out how to pay for it," Kelly says.

Then came the struggle with schooling. Kelly felt her daughter wasn't getting the education from public school that she needed to grow and succeed. "As a mother of an autistic child, I want my child to be able to go to a typical school, but I'm a believer that in many circumstances, special kids need special schools," she says. Children with autism require education taught in a different manner and constant sensory input.



Kelly and her friend Dorie Hoewel, the mother of a high-functioning autistic child, decided to make a difference. Almost five years ago, they started planning to build a school for autistic children. They raised funds, incorporated and started developing. After achieving 501c3 status, they started building and hiring. They received Illinois State board of Education certification, and opened the school's doors in December 2007. Since then they have expanded to the space next door and hope to continue to expand.

The Alexander Leigh Center for Autism is comprised of two venues: the Developmental Learning Center and the Therapeutic Day School, a year-round school that takes the place of public school. "We work on academic skills, socialization and daily living," she says. Kelly describes everything taught as intentional. "We have to keep in mind that while typical kids may learn 100 things, kids with autism may only learn 50," she says. "We have to be selective."

It is their goal to provide autistic children with the environment to develop their academic, emotional, social, communicative and physical skills to their full potential in order to achieve functional independence. Through the school, Kelly and Dorie have made a difference in many families' lives and feel everything happens for a reason. "It all connects itself," Kelly says. "I feel like this is what I'm supposed to be doing."

If you have concerns about your child's development, speak to your pediatrician about getting your child screened for autism. If diagnosed, early intervention is extremely critical for a maximum benefit from current therapies. Although there are no fully effective treatments and no cure, research shows that early intervention in an educational setting can result in vast improvements for children with autism.

Signs of Autism

Autism and Language: Starts talking later than other children, loses ability to say words or sentences, speaks with abnormal tone or rhythm, repeats words of phrases but doesn't understand their meaning

Autism and Behavior: Performs repetitive movements, such as rocking, spinning or hand-flapping; develops specific routines or rituals; becomes disturbed

Autism and Social Skills: Doesn't respond to his/her name, bad eye contact, appears not to hear you, resists affection, appears unaware of other's feelings, prefers playing alone