FIRST PERSON

brady, our firstborn son, has autism

By Mei Yeh-Kennedy

Mei Yeh-Kennedy, PhD, holds a doctoral degree in educational technology from Capella University. She is a corporate liaison at Viable *(www.viable.net)*, a video relay service provider. She lives in Austin, Texas, with her husband, Parker, and their two boys, Brady and Riley.

Brady and His Family Enjoy Smooth Sailing at First

I first held Brady on February 20, 2003. The first week was a bit rough—he had to be treated at the hospital for jaundice—but after that, it was smooth sailing. Brady was an easygoing baby, always happy and attentive. My husband and I did notice that he met physical milestones at least a few months behind his peers, though. For example, he sat up at 8 months, crawled at 10 months, and walked at 15 months. But our doctor assured us that this was fine because our son was still within the normal age range for achieving these milestones. (Readers can get more information on developmental milestones and developmental delays from First Signs, a nonprofit organization, at *www.firstsigns.org*.)

Brady had awesome eye contact, and he loved it when we read books aloud to him. By the time he was about 20 months old he could recite the alphabet; count to 20; label many items, including farm animals and body parts; and sign words such as *movie*, *sit*, and *finish*.

Above: Brady celebrates his 4th birthday.
Far right: Brady and his family.

Inattentiveness and Language Loss Signal That Something May Not Be Right

As Brady approached the age of 2, we noticed that he hadn't started making two-word combinations, and that it was increasingly difficult to get his attention. We thought he might have a hearing loss, since it runs in both of our families. Even though he'd had a hearing screening at birth, we took him for more hearing tests, three in 6 months, which prompted the audiologist to tell me, "You have to accept that Brady is hearing!" Actually, I wasn't worried about him being hearing at all, but my mother's intuition told me that something didn't seem right. We struggled to understand what it was. Was Brady's language being affected because we, his parents, were deaf? Was he getting insufficient exposure to an auditory environment?

We didn't dwell on these questions for long, however, because Brady gradually started to lose language. He wasn't labeling as much as before. We also noticed that we had to put a lot of effort into getting eye contact from him. He started walking back and forth by the TV, repeatedly taking one or two steps forward and then one or two steps backward, sometimes while clapping his hands. He declined to a point where we knew we needed to get help.

We sought evaluations, but the people we spoke to didn't seem to understand what was happening either. A psychologist told us, "Brady does not have autism because he interacts with people well."

Photos courtesy of the Yeh-Kennedy family

On top of all of this, I was due any day with my second child.

Growth in Autism Awareness Outstrips Medical System's Coping Ability

Autism awareness is spreading like wildfire. Diagnoses have increased at an astounding rate. The statistic most often quoted is that 1 child in 150 has autism. By comparison, the rate for childhood leukemia is 1 in 25,000, childhood muscular dystrophy 1 in 20,000, and juvenile diabetes 1 in 500. Yet autism receives less than 5 percent of the research funding of many less prevalent childhood diseases (Talk About Curing Autism, 2008). As if the high rate of autism diagnoses were not worrisome enough, many doctors are not properly trained, or kept up to date, on how to detect autism at the earliest possible age. And in many cases, once parents learn that their child has autism, the medical system has little to offer beyond that diagnosis.

Even though there are many good books and websites that describe autism and how to detect it early, parents still face the tremendous challenge of obtaining early intervention and other forms of support. This is probably why celebrities such as actress Jenny McCarthy, whose son, Evan, has autism, have become outspoken advocates of better services.

There is no known cure for autism, but there are stories of children who have recovered through early intervention and biomedical approaches. There is no known cause, either, though the medical field claims that several factors, including genetics and environment, may be responsible. It is also a controversial question whether vaccines play a part in causing autism symptoms. Brady received all the usual vaccinations until age 3, at which point we decided to stop. Our younger son did not receive any vaccinations after the age of 6 months.

Brady Gets a Diagnosis

Acting on a recommendation from an acquaintance, we contacted a state agency, the Interagency Council on Early Childhood Intervention, ECI. (We were living in Maryland at the time.) We learned that Brady was eligible for service because of his expressive language delay. This was a whole new ball game, and, unfortunately, the experience was not positive: We were battling with professionals who we felt did not understand our culture, our language, or our child. Though we constantly tried to educate them about our needs as Deaf parents, as well as the traits of our son that seemed atypical of autistic children, they consistently failed to acknowledge what we were telling them. Nevertheless, the experience made me stronger. I was learning the hard way what felt right for my son and what didn't. It was the hardest thing I've had to experience as a mother—to be very intuitive and be a fighter. Further, my husband and I spent so much time talking and trying to decide what was best for Brady that we didn't spend enough time grieving or coping with the diagnosis. Brady doted on his new baby brother, however, and started attending pre-early childhood education class twice a week.

After several evaluations, a psychologist formally diagnosed Brady with pervasive developmental disorder when he was 38 months old. We dove into researching online—our only source of information. Believe me, this is a vast, confusing sea in which to swim. I've compiled a list of some of the many signs of autism published on the Internet, boldfacing the ones I noticed in Brady

ORGANIZERS OF 2006 DEAF AUTREAT OVERWHELMED BY ENTHUSIASTIC RESPONSE, RESTRUCTURING GROUND-BREAKING CONFERENCE TO ACCOMMODATE ATTENDEES' DEMANDS FOR ASSISTANCE AND INFORMATION

Dear Friends:

I am a deaf mother of a deaf son with autism. In the spring of 2006, I established the very first Autreat for Deaf and Hearing families with deaf or hearing autistic children along with my co-chairperson, Stefanie Ellis-Gonzales, a fellow deaf mother of a deaf child with autism. This groundbreaking retreat was held at Camp Lakodia in South Dakota on April 7–9, 2006.

The autreat was such a tremendous success that it was truly a rewarding experience for all. A total of 22 parents, 16 children, and 8 speakers were part of this first-ever event. Information, ideas, and encouragement were shared during those few days that could not have been possible elsewhere.

Plans for the Second Deaf Autreat in the spring of 2008 have been put on hold due to the tremendous demands put on the original committee that created the initial Deaf Autreat.

The response by attendees of the Deaf Autreat resulted in a demand for assistance and information to meet the needs of:

- Deaf autistic children of deaf parents
- Deaf autistic children of hearing parents
- Hearing autistic children of deaf parents

The Deaf Autreat Committee needs to restructure the original goals and priorities to meet the above needs mandated by the attendees of the first conference. The committee also is in the process of working with the American Society of Autism (ASA) to obtain collaborative support as groups with mutual interests. Therefore, the second Deaf Autreat conference plans will be announced at a later date.

The logo as seen above was designed by a deaf parent of a deaf autistic child who participated in the Autreat. The sign in this picture is the new official sign for autism. The hand that is going inside symbolizes the autistic person's inclination to be engaged within the own self, and the cupped hand represents his world, or a protective layer, where the autistic person retreats. The sign also represents "inclusion and involvement" in which the autistic individual serves as a reminder of how vital it is to give and receive love and attention, which are essential to humanity.

For more information about Deaf Autreat, please feel to contact me at deafautism@hotmail.com

With warm regards,

Rosangela George
Deaf Autreat Chair

Join a new study on
Autism Spectrum Disorders and Deafness

Has your Deaf Child been diagnosed with Autism?

Videotapes of your child's First and Second Birthday are being collected to investigate early signs of Autism in Deaf Children

You will receive a $25 Gift Certificate for participation and a copy of your child's birthday on DVD

Parents please email Christen Szymanski@gallaudet.edu for more information

All videotapes will be returned

This project has been approved by the Gallaudet Institutional Review Board between the ages of 24 and 30 months:

Social Skills

- fails to respond to his or her name (**not all the time, but enough for us to notice**)
- has poor eye contact (**began after age 30 months**)
- appears not to hear at times
- resists cuddling and holding
- appears unaware of others' feelings
- seems to prefer playing alone—retreats into his or her "own world"

Language

- starts talking later than other children
- loses previously acquired ability to say words or sentences (**began after age 24 months**)
- does not make eye contact when making requests (**not all the time, but enough for us to notice**)
- speaks with an abnormal tone or rhythm—may use a singsong voice or robotic speech
- can't start a conversation or keep one going
- may repeat words or phrases verbatim, but doesn't understand how to use them

Behavior

- performs repetitive movements, such as rocking, spinning, or hand flapping (**the routine of walking back and forth by the TV began at age 30 months**)
- develops specific routines or rituals
- becomes disturbed at the slightest change in routines or rituals
- moves constantly
- may be fascinated by parts of an object, such as the spinning wheels of a toy car
- may be unusually sensitive to light, sound, and touch

The point I am trying to make here is that parents shouldn't wait for more than one red flag or accept a doctor's assurances. As soon as parents notice even one of the signs, they must push for evaluations and assistance. It can take a long time to obtain a diagnosis, but you want your child to get all the interventions as early as possible.

Left: Brady loves to play outdoors.

Some Battles Are Lost, But More Are Won: Insurance, Treatment, and the Right School Setting

At first it was a constant battle with the insurance companies to get the services Brady needed. Our health insurer kicked us off our health plan as soon as it found out about Brady's formal diagnosis of autism. Brady now has his own health insurance through the Texas Health Insurance Risk Pool, for which applicants are eligible if no other insurance plan will accept them. The annual cost of Brady's therapy is now nearly $45,000, but it is not covered by the Risk Pool insurance. As *The New York Times* has reported, "Most insurance companies do not pay for therapy for developmental disorders like autism, though a few companies offer reimbursement as part of their health benefits" (Tarkan, 2002, para. 23).

We didn't agree with the school district in Maryland about the setting where Brady would be placed when he turned 3. We felt strongly that he would benefit tremendously from a peer learning environment where there was a good mix of levels, but the district wanted to place him in a less heterogeneous setting. We were already burned out from fighting ECI and the health insurer, so we didn't waste a lot of time before we started looking for another school district.

Within a few months we decided to move to Austin, Texas, where our son now attends a mainstream preschool program within the Eanes Independent School District. His class has a good mix of normally functioning children and children with special needs. At the same time we were looking for a new district, we were eyeing a private clinic that provided applied behavior analysis (ABA) therapy. Much research has been published on the success of ABA therapy with children with autism. In a 1999 report, the U.S. Surgeon General wrote, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior" (U.S. Department of Health and Human Services, 1999, p. 164). Several other therapeutic approaches have gotten favorable reports, such as relationship development intervention, play therapy, and sensory integrated therapy. Children with autism also benefit from speech and occupational therapy, which typically is offered through school.

However, attending school and receiving ABA therapy was not the only treatment we wanted to pursue for Brady. We wanted to try other approaches as well while our son was young. It was overwhelming to try to figure out which to try. That was half the battle; the other half was getting Brady to willingly participate in the treatment. We took him to a doctor associated with Defeat Autism Now!, a project of the Autism Research Institute that educates parents and medical professionals about biomedical approaches to treating autism. He had a battery of blood tests done. The one thing I remember this doctor saying to us was, "Do you know who will be Brady's best teacher?" We answered, "Us, his parents," and he said "no," and pointed to Brady's youngest brother, who was 8 months old at the time. And he was right.

With Clinic and School Settings in Place, Things Start Going Brady's Way

After living in Austin for five months, Brady finally started attending the private clinic 10 hours a week. He'd been on a waiting list since we'd moved. Perhaps it could have been worse. As *The*

Left: Brady learns the most from his best teacher, his younger brother, Riley.

New York Times has reported “Even parents who decide to pay for treatment have trouble finding private specialists. Autism schools and private behavioral therapists typically have waiting lists of more than a year” (Tarkan, 2002, para. 26).

Brady currently attends his mainstream preschool program in the Eanes Independent School District 28 hours a week while continuing to go to the private clinic 10 hours a week. He keeps making progress. Two weeks after he started school, his teacher wrote, “The past few days he has gotten really sad and even cried during {a particular} song. I pulled him to the back of the circle today when the song started and he walked around the circle and then got right in the middle and clapped his hands and smiled the whole time. He dropped to the floor and then got back up every time the song called for it. Very appropriate and engaged! We heard lots of language today too!”

In May 2007 Brady’s teacher wrote, “He’s been saying, ‘I want ______’ with less prompts and following the arrival routine with less prompts. He’s doing better with ‘look at me’ but still needs to work on it and also walk with me. His correct production of words is difficult for him, but he tries.”

This is from December 2007: “Today {a classmate} discovered feathers in the art center & she was tickling us with it. Brady loved it! We were able to get him to chose if he wanted to be tickled on his arm or leg & he was saying ‘more tickles please’ to {a classmate}. Very sweet interaction!”

But as the doctor had predicted, Brady’s younger brother, who is now 2 years old, is his best teacher. He prompts Brady to participate and is very patient when Brady doesn’t do what is asked of him the first time. When we go out in public, we can never predict how Brady will behave. Some days he’ll seem normal to public eyes; for instance, he’ll be able to sit with us. Other days he’ll try to run all over the place. Brady exhibits interest in a variety of things, though he also shows interest in specific things and has his favorite items. Overall, he has shown a good ability to rotate interest. He loves the computer and is capable of navigating through programs independently. He also loves being outside—running or being on the swing. When he is home, he frequently engages in self-stimulating behavior, or stimming—which continues to consist of walking back and forth by the TV. His therapist has said that most families see that because the child is releasing stress from “behaving as the society expects” during the day. This is what makes it difficult for us to get Brady involved in family activities at home. His expressive language is still limited to asking for what he needs. He is still not able to initiate conversation or talk about his day at school.

We Learn We’re Not Alone: Building Community With Other Families Like Ours

As time passed, I talked more with the doctor and read more, and the information I’d been hearing finally began to make sense to me. The Internet was still our family’s main source of information about resources and services for children with autism. But as informative as the Internet was, we craved to learn more about how other families, especially deaf families, were doing with their autistic child. We desired opportunities to meet with other families to learn about what they did or tried or heard about from others. But it was a challenge to communicate face to face with hearing parents. For the most part, we did so by e-mail and video relay.

In the last couple of years we have begun to participate in Deaf Autism, a web-based community for families with members who are deaf or hard of hearing that have a child with autism (see *http://www.deafautism.com*). We and the other parents involved with Deaf Autism are working together to meet a common challenge: incorporating ASL into all aspects of our children’s learning environments to help them become fluent in both ASL and English. These parents are a crucial support group for our family.

We were thrilled when the first Autreat was held in 2006. Autreat is a retreat for families with deaf or hard of hearing children with autism that is led by Rosangela George in association with Deaf Autism. Unfortunately, I was unable to go, but parents who did attend spoke highly of the face-to-face opportunity to learn from and interact with other families in our native language and to share common experiences within our culture. (For more information on Autreat, see *http://www.deafautism.com/autreat.html.)*

Like all families with an autistic child, we hope we are on the right path to our child’s recovery and that we will be able to provide him access to every possible opportunity for growth.

References

Talk About Curing Autism. (2008). *Latest autism statistics*. Retrieved from *www.talkaboutcuringautism.org*

Tarkan, L. (2002, October 22). Autism therapy is called effective, but rare. *The New York Times*. Retrieved from *http://www.wrightslaw.com/news/2002/jaynes.tarkan.nytimes.htm*

U.S. Department of Health and Human Services. (1999). *Mental health: A report of the Surgeon General*. Rockville, MD: National Institute of Mental Health.