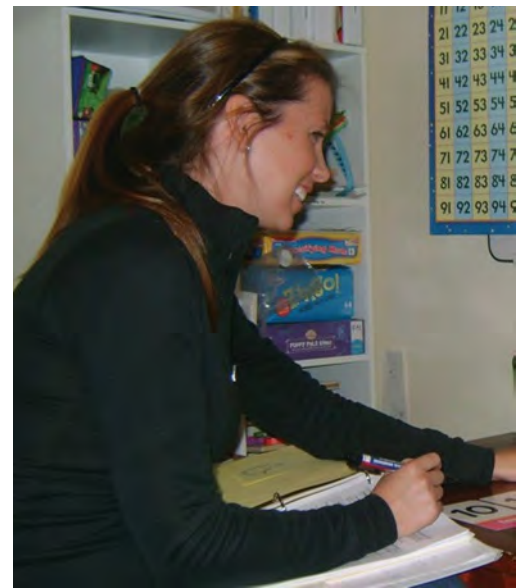


# Family Matters

## Enlisting the Family to Ensure Successful Early Intervention for Children with Autism Spectrum Disorders

By Robert Putnam, Ph.D., BCBA-D  
and Patricia Ladew, May Institute



### Five-year-old Caleb Dills

pesters his mother for attention, rattles on his classmates, and sometimes forgets that 14 comes before 15. You might think that he is a typical kindergartener, but you would be wrong. Caleb was diagnosed with autism when he was 2. But, thanks to early diagnosis and effective intervention and treatment, Caleb has made amazing strides in the past few years. Today, he attends a full-time kindergarten with typically developing peers.

Readers of *Exceptional Parent* were introduced to the Dills family from Fort Benning in Georgia back in April of 2008, immediately after Caleb was diagnosed. His parents, Salina and John, a first lieutenant, were very concerned about what the future would hold for Caleb. Today, they are eager to provide an update to their son's story so other parents who have children recently diagnosed with an autism spectrum disorder (ASD) will know that successful outcomes are possible and that they have every reason to be hopeful.

"I think it's so important for parents to know that it's not the end of the world when they get that diagnosis," says Salina. "They need to know that somewhere, somehow, there are people who can reach their child and make a difference."

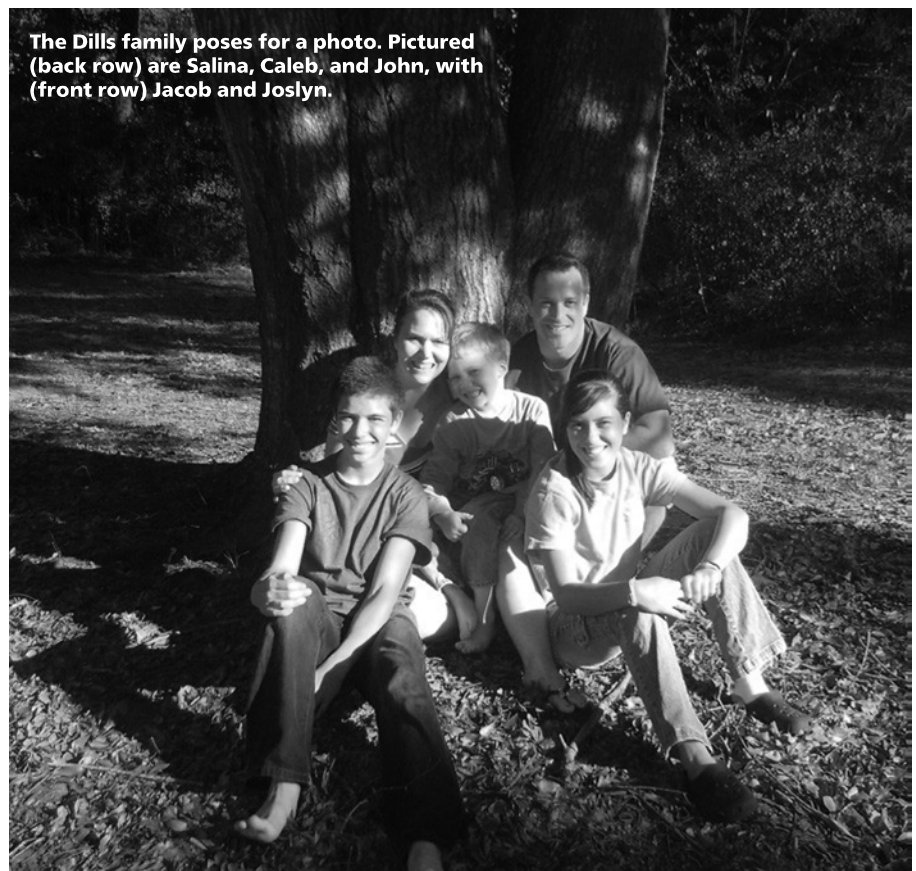
After Caleb's diagnosis, Salina and John found Anne Stull, M.A., LPA, BCBA, a board certified behavior analyst with May Institute, a national nonprofit that provides educational, rehabilitative, and behavioral health services to individuals with special needs. Anne, who worked out of the Institute's Center for Autism Spectrum Disorders in Columbus,

Ga., came to the Dills' home four to five days a week. She immediately began addressing Caleb's inappropriate behaviors and inability to speak more than 10 words.

"One of the biggest things we did in the beginning was addressing compliance, or basic direction following, like getting him to sit down to work with me," says Anne. "It was an uphill battle at first. Caleb was this precious little boy who didn't have words or ways to communicate his needs, so he screamed and threw tantrums to get the things he wanted."

Using the principles of applied behavior analysis (ABA)—positive reinforcement, teaching in small steps, prompting, and repeated practice—Anne patiently taught Caleb to sit down at a table and work with her without screaming or throwing a tantrum.

ABA has been endorsed by the National Institutes of Health and has been identified by the Surgeon General of the United States as the most effective way to treat autism spectrum disorders (ASD). According to the National Autism Center's National Standards Report (2009), data collected through hundreds of



**The Dills family poses for a photo. Pictured (back row) are Salina, Caleb, and John, with (front row) Jacob and Joslyn.**



**Claire Herndon, a May Institute Behavior Specialist, works with Caleb on his academics during an afternoon home-based session.**

studies indicate that ABA is a highly effective method to teach children and adolescents with ASD. ABA is the only treatment reimbursed by TRICARE's Extended Care Health Option (ECHO) and Enhanced Access to Autism Services Demonstration ("tutor") programs for military families who have children with ASD.

Intensive early intervention services that incorporate an ABA approach have been found to greatly improve the lives of children with ASD. These services focus on developing communication, social interaction, and basic functional skills in children, as well as reducing their problematic behaviors. The results impact all areas of their lives. When children with ASD can communicate and interact with others, they are more likely to succeed in school. And research confirms that improving a child's communication and social skills will also improve the quality of life for the child and his or her family.

### **Helping Caleb Find His Words**

Once Caleb was able to sit down and cooperate with Anne's requests, she introduced the picture exchange communication system, or PECS. A form of alternative and augmentative communication (AAC), PECS uses pictures instead of words. A child can exchange a picture icon of an object (such as an apple) or activity (such as a swing set) for the actual object or activity. This is effective because it is easier for many children with ASD to initially communicate their needs and desires through picture exchanges than through verbal exchanges (words).

Once the child learns simple picture

exchanges, the communication can become more complex – communicating full "sentences," or responding to questions. PECS helps children acquire language and learn to talk. This, in turn, helps reduce the frustration that stems from not being able to communicate. Research has shown that PECS assists nonverbal children acquire spoken language faster than many other methods.

"Caleb did really well with PECS," Anne says. "Soon he was able to ask for very basic food items he wanted. Then he moved on to requesting toys and activities."

"It was amazing," Salina says. "He just flew through the PECS system. We started with word approximation, so if he was trying to say 'banana,' and he said 'ba,' he would get a reward. He started to gain speech really quickly."

During this time, Caleb also worked with a speech therapist who taught him exercises to develop the muscles around this mouth that had been underutilized due to Caleb's inability to speak.

Caleb made progress rapidly, learning all his colors, shapes, animals, and the names of basic household items. And then, one momentous day, Caleb and Salina had a very special moment.

"It was just an ordinary day and I was standing in the kitchen preparing a meal," remembers Salina. "Caleb walked up to me and tapped me on the leg and said 'Mama.' All I could do was just bend down and hug him. I was beyond happy. It was truly an answer to a prayer that he knew who I was and could call me 'Mama.'"

### **Getting the Family Involved**

"I have to give a lot of credit to Salina because she didn't know anything about ABA when we started," Anne says. "I explained to her that Caleb was screaming and throwing tantrums because that was how he got people to give him what he wanted. If he screamed because someone asked him to do something, then they wouldn't make him do it. If he screamed because he wanted someone to make something better for him, that's what they would do. In ABA terms, I explained to her the function of Caleb's behavior—why he was doing what he was doing. This really

opened her eyes and changed her world."

"Anne educated me about behavior therapy and how we were inadvertently reinforcing some behaviors that weren't what we wanted," says Salina. "We wanted to extinguish those behaviors (screaming and throwing tantrums) and replace them with behaviors we wanted."

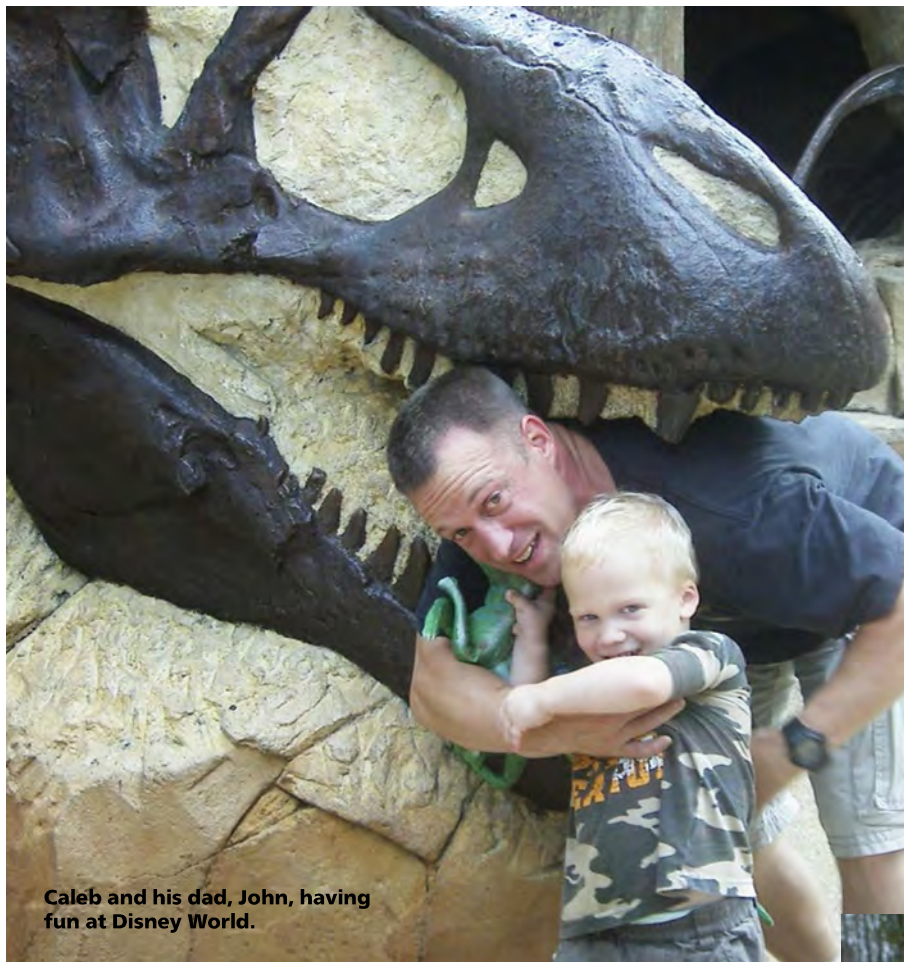
Salina embraced ABA and followed Anne's example of only responding to Caleb's appropriate behavior, not to screaming and tantrums. So did Caleb's Dad and his siblings Joslyn and Jacob. "Salina was doing it. John was doing it, Jacob and Joslyn were doing it—everybody was implementing ABA," says Anne. "They saw that Caleb could learn and he could tell them what he wanted. And once no one in his life was accepting him screaming or throwing a tantrum to get what he wanted, he stopped doing those things. Getting Salina on board was a breakthrough," says Anne. "Now she's is a huge 'ABA Mom.'"

It is very important that all family members consistently implement interventions taught by the ABA therapist. If everyone in the child's environment recognizes and responds to him when he uses his communication system or words, he will continue to do so. If they don't recognize and respond to him when he is using his new communication methods, he will revert to what has worked before. In Caleb's case, this meant screaming and throwing tantrums.

### **Accentuating the Positive**

In addition to ignoring bad behavior, the Dills learned to give Caleb praise, attention, and other positive "reinforcers" such as favorite activities when he behaved appropriately. "We made a huge, huge fuss over the good things," explains Salina, "basically ignoring the things we didn't like, not giving any kind of attention to them, negative or otherwise. We're all motivated by positive attention, but some kids don't distinguish between positive and negative attention. To them it's just attention and that's what they want."

Caleb thrived on the positive feedback. He would eagerly complete his work, striving to "get it right" so his parents, siblings, therapists, and teachers would appreciate his



**Caleb and his dad, John, having fun at Disney World.**

efforts. “He loved for me to tell him he had done a great job,” says Anne.

Today, Caleb’s reward system is based on earning stars. If he earns six stars during a therapy session, he gets a “reward” such as playing robots with his brother, building a fort with Salina, or watching a movie with his dad.

The success of the early intervention and effective therapy that Caleb has received is evident in the many milestones he has achieved over the past several years—from learning words and speaking in sentences; to learning how to color, draw, and write; to learning how to say ‘please’ and ‘thank you;’ to learning how to wait.

Learning manners and how to sit still and wait helped make Caleb’s transition to kindergarten easier this year. He was able to use or “generalize” these skills in the school setting. Although he is doing a good job of keeping pace with his typically developing peers, there are some things he struggles

with such as “sight words”—words that children are expected to recognize on sight without needing to sound them out.

May Institute Behavior Specialist Claire Herndon, Caleb’s new therapist, is working with him at home on sight words. She also works with him on phonics, and sounding out “blended” letters like “br” or “bl.” “We recently discovered that he was losing some of his letter sounds,” explains Claire, “so we are also working on skill re-acquisition and maintaining the skills he has already acquired.”

Practicing and maintaining skills is critical when teaching children with ASD. So is learning to use those skills in front of other people, in different settings, or with unfamiliar materials. Because children

with ASD often have difficulty in these situations, reinforcing the things they have already learned is a key part of their therapy.

Although the work is difficult and the challenges are many, Caleb continues to make progress. He has been undergoing independent evaluations on a regular basis since he was first diagnosed. “At first, he was aging faster than he was gaining speech,” Salina reports. “But ever since that first evaluation, he has always gained speech. He’s slowly been reducing the gap between where he is and where his peers are. Now, on average, he’s actually age equivalent, or within the norm.”

### **Continuing to Learn and Grow**

Caleb and his family were sad to say goodbye to Anne when she moved to North Carolina last year to help open another May Center for Autism Spectrum Disorders near Camp Lejeune. But Salina is delighted that May Institute is continuing to expand its services to military families throughout the country.

“I’m thrilled to hear that May is branching out to other installations. I know we’re not



**Caleb enjoys time with Anne Stull, a board certified behavior analyst with May Institute and his first therapist, while on an outing to a farm.**

going to be here at Fort Benning forever and that scares me for Caleb's future. I hope that if we move we will be able to access such effective services."

Salina has many hopes and dreams for Caleb's future. "I want autism to become irrelevant in his life," she says. "I'd like to see him be in a place where, yes, although he has autism, it really doesn't restrict much what he wants to do or how he interacts with others. I'd like to get to a point where Caleb doesn't need me anymore and is not dependent on the services of therapists to be able to learn and grow and develop. He's not there yet. He still needs those specialized services. But we have every reason to be optimistic because thus far, every goal we've had for him, he's achieved."

"He is such a super star. I'm so proud of him," says Anne, who stays in touch with the Dills family through regular phone calls. When Anne joined Caleb and Salina on an outing to the zoo this summer, she remarked on how much he had grown.

"Yes," Caleb happily agreed, "and I'm growing every day!" •

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Patricia Ladew is Senior Communications Writer for May Institute's Office of Communications. She has specialized in healthcare writing for more than 20 years.

### **Serving Military Families Across the Country**

May Institute's Centers for Autism Spectrum Disorders (ASD) in Georgia, Alabama, North Carolina, Tennessee/Kentucky, Texas, Florida, and New England are dedicated to meeting the immediate and pressing need for services for children with ASD in all branches of the military—Army, Marines, Navy, Air Force, and Coast Guard. The Institute plans to continue expansion of its services for military families through new Centers in close proximity to key military installations.

## **About Early Intervention**

By Anne Stull, M.A., LPA, BCBA, May Institute

Children up to the age of 3 with an autism spectrum disorder (ASD) are eligible to receive early intervention services such as speech therapy, occupational therapy, physical therapy, play therapy, and/or applied behavior analysis (ABA) therapy. These services are provided under federal law through the Individuals with Disabilities Education Act (IDEA). Part C of this Act details a federal mandate for services for young children with special needs, birth to 3 years of age.

Some military installations have early intervention services specifically for families living on the installation. For example, children with ASD living on the base at Camp Lejeune in North Carolina receive services from the Education and Development Intervention Services (EDIS). Families stationed at the installation, but living outside of the base or post, receive services from local child development centers in the community. Service coordinators from these centers identify services for which the children are eligible, provide information about resources in the community, and assist families in obtaining these services.

Applied behavior analysis (ABA) is the only treatment reimbursed by TRICARE's Extended Care Health Option (ECHO) and Enhanced Access to Autism Services Demonstration ("tutor") programs for military families who have children with ASD. Through ECHO, military families are eligible for \$36,000 per fiscal year for ABA services. Once enrolled in ECHO, families can contact a qualified ABA service provider to set up home-based services.

ABA facilitates the development of language, social interactions, and independent living by applying basic behavioral practices (i.e., positive reinforcement, teaching in small steps, prompting, and repeated practice). ABA can also help reduce social problems and inappropriate behaviors, such as noncompliance, aggression, and stereotypical behaviors, such as hand-flapping, body-rocking, and spinning or lining up objects.

At May Institute, these services begin with a full assessment that usually includes parent interviews and questionnaires, multiple observations, and skills assessments. A behavior analyst—a board certified practitioner who has undergone extensive training and supervision—will review results with the parents. They discuss skills that need to be targeted for acquisition and the behaviors that need to be targeted for reduction. He or she will then develop an individualized treatment plan for the child.

Although each treatment plan is tailored specifically for the child for whom it is written, a typical early intervention treatment plan may consist of the following: increasing appropriate behaviors (e.g., compliance, waiting); increasing communication skills (e.g., requesting, labeling); increasing social skills (e.g., sharing, initiating interactions); increasing adaptive living skills (e.g., toileting, eating); and increasing pre-academic skills (e.g., counting, letter identification).

Once the individualized treatment plan is developed, the behavior analyst reviews all of the goals for skill acquisition and programs for behavior reduction with the parents. The parents then receive personalized training as the home-based therapist implements the goals and programs in their home. There, parents can observe and ask questions on how to begin implementing these programs themselves. In this way, they become members of their child's "therapy team," a group that may include other professional such as speech and language pathologists, occupational and physical therapists, teachers, educational consultants, and respite care providers.

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Anne Stull, M.A., LPA, BCBA, Clinical Director of the May Center for Autism Spectrum Disorders in Jacksonville, N.C., is a licensed psychological associate and a board certified behavior analyst. Anne served as Clinical Director at the May Center for Autism Spectrum Disorders outside Fort Benning, Ga., before moving to Camp Lejeune last year.