

Building Life Skills for Children with Asperger Syndrome

By Eileen G. Pollack, MA and Dennis C. Russo, PhD, ABPP

It took Captains Ada and Victor Cotto almost six years to get a proper diagnosis of Asperger syndrome for their son, Jose. In the years in between, Jose was misdiagnosed with anger management issues and then with attention deficit hyperactivity disorder (ADHD). His atypical behaviors and difficulty communicating with others created challenges at home, in school, and in the community. The family often avoided social outings that would inevitably lead to uncomfortable situations.

It was not until a child psychologist suggested that Jose be evaluated for Asperger's that Ada and Victor discovered what was at the root of their son's struggles.

"I had never heard of Asperger's before," says Ada. "I just knew I could not communicate with my kid. I had spent countless nights just sitting on the bed crying, not knowing what I was doing wrong."

Ada and Victor, who are both on active duty and stationed at Fort Benning, GA, quickly educated themselves about Asperger syndrome, which is considered to be a milder form of autism. They also learned that, because Asperger syndrome is not as easily recognizable as autism, it is often misdiagnosed. And they learned that effective treatment could make a world of difference in their son's life.

Understanding Asperger Syndrome

Children with autism and Asperger syndrome tend to share a number of characteristics, including difficulties with traditional school tasks and settings, and

varying degrees of ability in the areas of communication and social interactions.

Unlike their peers with autism, children with Asperger syndrome often develop typical language, cognition, and self-help skills. In fact, they often have impressive vocabularies. Where they might have difficulty is with subtleties in language such as irony and humor.

The greatest challenges for these children often involve social skills and understanding the nuances of social interactions. Unlike many children with autism who seem somewhat aloof or uninterested in others, children with Asperger syndrome usually want to interact with others, although they may be very awkward in social situations.

These children often have difficulty engaging in conversations, joining in play activities, and initiating and maintaining friendships. And, although their intelligence may be average or above average, many struggle in school because they have difficulty managing assignments, maintaining attention throughout class, and working in groups.

Difficulties in school, along with their

inability to relate easily to peers, can be stressful and stigmatizing for these children, especially in their adolescent years when there is such an emphasis on having friends and fitting in.

Seeking Support

For 13-year-old Jose, an accurate diagnosis meant that his parents and teachers began to understand his behaviors and challenges in a whole new light. It also helped explain Jose's isolation in school and lack of meaningful contact with other kids.

"Jose had no friends and no social interactions," shares Ada. "He would sit in a corner by himself during his lunch hour and read a book."

Even worse was when Jose's efforts to reach out would fail. "There's your kid who is just trying to establish a conversation with another kid, and then they bully him or make fun of him or completely ignore him," Ada recalls. "Jose would come back and say, 'You see why I don't talk to anybody. Everybody hates me. I hate this.'"

Ada and Victor researched options for programs for Jose and discovered the

One of the mainstays of ABA is teaching in small steps. ABA therapists like Jade combine teaching in small steps with positive reinforcement, prompting, and repeated practice. For children with Asperger's, these teaching strategies help children to improve behavior and develop important social skills, as well as to "learn how to learn."

Captains Victor and Ada Cotto with daughter, Gabriella, and sons, Jose and Andrew (kneeling) on vacation in Puerto Rico.



Southeast Regional Autism Center in Columbus, GA. A program of May Institute, the center specializes in using applied behavior analysis, or ABA, to teach social skills and other important life skills to children with autism, Asperger syndrome, and other developmental disabilities.

Steps to Success

May Institute's work with individuals with disabilities is centered on building the necessary skills to live as independently and productively as possible. Because one of the markers of success

is the ability to interact with others, the organization's goals for educating children with Asperger syndrome are often focused on skills of higher functioning, including social development.

Jade Lewis, MEd, BCABA (Board Certified Assistant Behavior Analyst) is a long-time behavior analyst with May Institute who was assigned to Jose and his family. They set to work developing a treatment plan that included goals for both home and school, integrating the fundamentals of ABA into every step. Rather than being punished for bad behavior, for example, Jade recom-

mended a reward system to enforce and recognize all the things Jose did well. She also worked with Ada and Victor on the parenting skills that are so critical when raising a child with special needs.

"Jade worked with us so that we could understand that Jose has a special way of seeing things," says Ada. "We had different sets of social rules. She helped us better understand Jose and his point of view."

Jade began accompanying the family on outings, like to the movies and the local pool. She helps Jose learn appropriate behaviors in different circumstances. "My husband and I are both company commanders, and Jade goes to military family days with us," explains Ada. "She'll prepare Jose ahead of time so he knows what to expect. During the outing, she will reinforce whatever they worked on in their previous session."

Jade also collaborated with Jose's school, where Jose's principal and teachers were having a difficult time with his behaviors. The team developed an individualized education program (IEP) for Jose, focusing on goals that would support skill development in the necessary areas. Recognizing that Jose was one of several classmates with a disability, the team brought the seventh grade class together for a discussion about differences and the importance of accepting their peers who didn't necessarily look or act or sound like everyone else. Raising awareness was one of the steps in Jade's plan to help Jose integrate more fully into his school.

Within months, Jose was making significant improvement. "Jose went from having zero friends to getting in trouble for talking too much with other children," Ada laughs. Because Jose speaks in a monotone voice (a common trait of Asperger syndrome), Jade recommended speech therapy, which the family has integrated into his treatment plan. "Jose doesn't express emotions when he talks; that was a barrier for making friends with other kids," his mother explains. Jade accompanies

Jose to speech therapy and works with him at home doing ABA therapy with his new speech skills.

ABA at Work

Justin Brewer, a friend of Jose's, is another 13-year-old boy whose family came to the Southeast Regional Autism Center seeking services for their son with Asperger syndrome. Justin's father, Sergeant Major Richard Brewer, and his stepfather, Major Charles Fisher, are very involved in Justin's life. Jade works with the extended family to provide services.

"Kids like Justin and Jose don't really have learning disabilities," says Marsha Fisher, Justin's mother. "So they fall into a niche that's difficult to serve in a classroom. Sometimes what they need is one-on-one attention—especially with social skills. These kids don't really get nuances sometimes. That can cause some trouble."

One of the mainstays of ABA is teaching in small steps. ABA therapists like Jade combine teaching in small steps with positive reinforcement, prompting, and repeated practice. For children with Asperger syndrome, these teaching strategies help children to improve behavior and develop important social skills as well as to "learn how to learn."

"With Justin, I first worked on organization and study skills," says Jade. "We break up homework into steps. Get out your binder. Find your assignment. Read the chapter. Answer the first question. He's worked hard and now has the process down."

"We also work on skills that help when he studies, like flash cards, and memorization skills, using little tricks like acronyms and mnemonic devices."

"Jade is skilled at breaking things down for Justin in manageable, bite-sized tasks," Marsha explains. "They are small enough pieces that he can grasp, and accomplish, and see progress."

Using Community as a Classroom

May Institute has long recognized that the best classroom is the real world.

Because the organization's teaching model is not center-based, but community-based, staff actively seek opportunities to work with students in the context of the world around them. If the ultimate goal is to give children and families the tools they need to live their lives, the best way to achieve that goal is to develop the ability to use new skills in the real world.

With that in mind, Jade took Justin and Jose to a local bookstore recently so they could "practice" social skills like interacting with each other as they looked at books and explored through the store. "It's nice to have the help because it's probably one of the most difficult things to teach a child," says Marsha, Justin's mom. "It doesn't come innately."

Marsha also appreciates the confidence that she sees growing in Justin as he learns new skills and accomplishes bigger and bigger steps. "Having adults who are patient and listening to what he has to say gives him the confidence to move forward," she explains. "His teachers tell me that he's more comfortable with himself, speaking a little more in school and asking more questions."

Looking Ahead with Confidence

Jade is confident that both Justin and Jose are on a positive trajectory. She envisions them going to college and living full, productive lives. "Developing the skills they're learning now, and being independent, will be very important for their future success," she says.

One of May Institute's primary goals is to develop expertise and skills in the people who support the children served. Therapists like Jade won't always be there to provide services, nor should they be. The better the skill set of a child's support system, the better the outcomes for that child.

Jade has been impressed with how hard the two families have worked to support the progress of the boys. "In both these families, the parents are really the ones who keep it all going," she

explains. "I set up the systems, but it's the families who implement them."

"Jose needed help, and he needed tools," Ada shares. "ABA therapy has transformed him completely. I can see he is happy now. I was so concerned about what kind of an adult he was going to be, but now I am very much at ease. I'm positive we have the tools to help him become the best that he can be."

Jose now has a few trustworthy, good friendships. These children come to the house to play, and he goes to their houses as well. That is something Ada and Victor could not have hoped for a few years ago.

Justin is also making great strides. He regularly plays with two other boys who live down the street—this is the first place they've lived where Justin has friends in the neighborhood. "Jade came along at just the right time," says Marsha. "Between May Institute and Fort Benning, I'm pleased to say that Justin is doing better than he ever has."

"Every child is unique and learns in his or her own way," Marsha says. "The key is figuring out what that is for your child and learning to plug into it." With individualized and ongoing attention, the proper tools, and the support of a community, families can be confident that their children can thrive, build relationships, and make plans for the future. •

Dennis C. Russo, PhD, ABPP (Diplomate of the American Board of Professional Psychology), is Chief Clinical Officer of May Institute. A recipient of the Lee Salk Distinguished Service Award from the Division of Pediatric Psychology of the American Psychological Association, Dr. Russo holds a faculty appointment at the Tufts University School of Medicine. He is a past president of the Association for Advancement of Behavior Therapy and the Society of Pediatric Psychology, and has been elected as a Fellow of the American Psychological Association. Dr. Russo is a 2008 Fellow of the Association for Behavior Analysis International (ABAI).

Eileen G. Pollack, MA is Vice President of Communications at May Institute. She has been involved in human services program development and management and corporate communications for 20 years.