



Marianne Idol, M.A., BCBA, a May Institute behavior analyst, works one-on-one with Ale in his home. Ale is learning to “stop,” using visual prompts.

Safety First For Children with Autism Spectrum Disorders

By Anne Stull, M.A., LPA, BCBA,
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All parents worry about their children’s health, happiness, and general well-being, but parents of children with autism spectrum disorders (ASD) and other developmental disabilities must often make extraordinary efforts to ensure that their sons and daughters are safe both inside and outside the home.

Children with ASD and other special needs may be more likely to act impulsively—to run away or wander—than their typically developing peers. This puts them in greater danger of becoming lost or getting hurt. If their families are in active military service, frequent relocations may make it even more difficult for them to be familiar with their surroundings or to distinguish a stranger from a friend. For these children, basic safety skills may some day become critical life-saving skills.

Like most parents,

Jose Ruiz, a Combat Engineer stationed in Camp Lejeune, N.C., and his wife Johan have done everything they can to make sure their home is safe for their three children, Hari (7), Ale (5), and Allyson (3). But they worry about Ale, who was diagnosed with autistic disorder in October of 2008. Ale loves to run away, a playful habit that could lead to a dangerous situation at home, school, or out in the community.

A Very, Very Big Concern

“He started running when he was about 3 years old,” says Jose. “And he can run very fast! When we take him out to the store, he could be standing right next to us and then all of a sudden ‘poof!’ – he’s gone.”

That was exactly what happened during a trip to the grocery store last year. One minute Ale was at his parents’ side, the next he was running down the aisle, heading for the door. Fortunately, the aisle was full of shoppers and he was not able to get past them.

“At school it’s the same problem,” Jose continues, describing how he once watched Ale jump right out of a swing and head for the gate of the school yard the moment his teacher started to announce that recess was over.

“We have learned that children with autism are very unpredictable,” he says. “For us, that represents a very, very big concern because if we’re not paying attention, he can literally disappear in a snap.”

Jose and Johan shared this concern with Ale’s behavior analysts – Marianne Idol, M.A., and Whitney Hendricks, M.A., – and they began addressing the problem immediately. Both women are board certified behavior analysts (BCBAs) with May Institute’s Southeast Regional Autism Center in Jacksonville, N.C., who work with families at Camp Lejeune and in surrounding areas. They have been working with Ale since October 2009, soon after the Center opened.

“It wasn’t until May Institute came to Jacksonville last year that we had access to applied behavior analysis (ABA) ther-

apy for Ale,” Jose explains. “We were on waiting list after waiting list...we were waiting for a good year before Ale started receiving ABA therapy.”

ABA is a methodology that applies basic behavioral practices to increase skills and appropriate behaviors and decrease inappropriate behaviors. It 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 with children with ASD.

Teaching a Child to Stop

Using ABA techniques that include breaking down tasks into small steps and providing lots of positive reinforcement and opportunities to practice, Marianne and Whitney have been teaching Ale to stop when asked. They work on this safety-related goal during their home visits, trying to make it as fun as possible.

“They started by walking right next to Ale and then stopping, walking and stopping,” explains Jose. “Now they are at the stage where they take a couple of steps forward just to see if he stays put, then call him and see if he comes forward, then ask him to stop again and see if he responds. They do this over and over and over again.”

Another fun and effective way



Jose is very proud of Ale’s great work with Marianne.

Marianne and Whitney teach Ale to stop is by using a sign that has a red “stop” sign on one side and a green “go” light on the other. They prompt Ale to stop when the stop sign is facing him and go when the green light is facing him, reinforcing the lesson by saying the words “stop” and “go” when they show the corresponding sign. This helps him associate the word with the request. With patience, persistence, and a lot of practice, Ale will learn to respond appropriately to the “stop” request in other settings and without the sign.

Depending on the child’s preferences, ABA practitioners provide “reinforcers,”

or rewards, such as praise, edible treats, or small toys immediately after a child gives the correct response. After the child consistently stops when requested, the behavior analyst may take him outside to practice. If he does not repeat, or “generalize,” the proper response to the “stop” request outside, they may go back inside for additional practice.

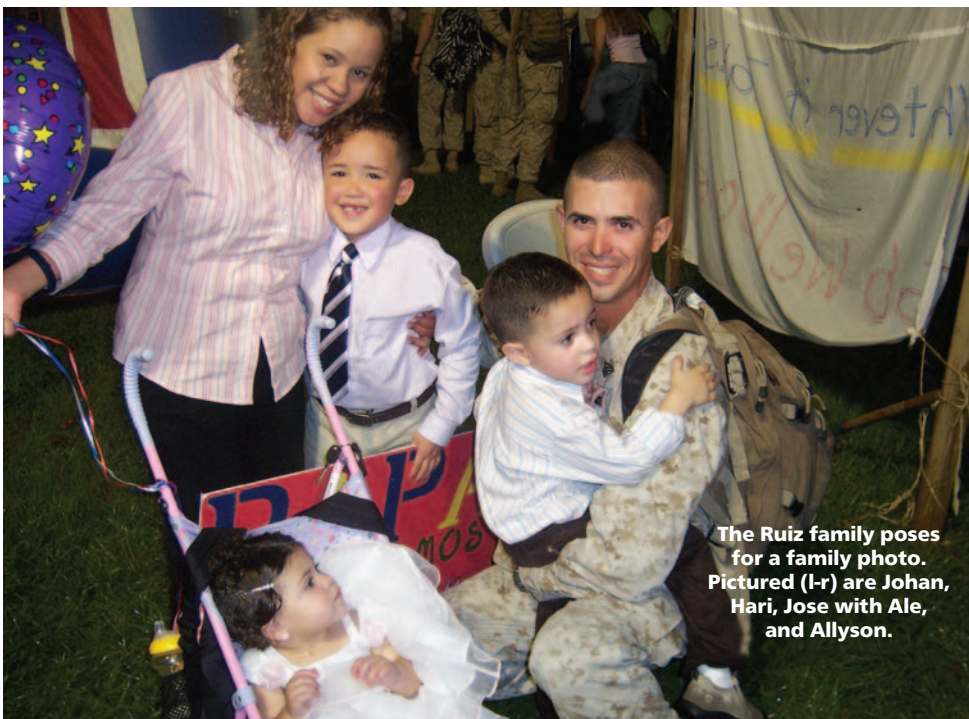
Ale’s favorite rewards are drawing and playing with Play-Doh. When he first began receiving in-home therapy, Marianne and Whitney used Play-Doh to keep his attention and encourage him to stay at the table.

Working with the IEP Team

When a school-aged child is receiving in-home ABA therapy, his behavior analysts usually become part of the Individualized Education Program (IEP) team at school. That way, they are able to offer input during the development of his behavioral support plan.

At Ale’s school, his behavioral analysts have “joined the team” that includes his classroom teacher, special education teacher, speech language pathologist, the principal, and his parents. The team meets to ensure that the treatment goals implemented at home are consistent with those implemented at school and vice versa. Because the team provides this consistency across settings and works toward shared goals, Ale has many more opportunities to practice. As a result, he can often master these goals more quickly.

There are ongoing opportunities to collaborate with the school’s team. A good example is Ale’s treatment plan and IEP, which were recently updated. Marianne, and Whitney met with his special education teacher to review his new treatment goals at home and his new IEP goals at school to ensure that they were consistent before implementing either of them. Working together, the team has created a comprehensive program with current goals and objectives that address Ale’s unique needs. Ale’s safety-related treatment goals for the next quarter include compliance (e.g.



The Ruiz family poses for a family photo. Pictured (l-r) are Johan, Hari, Jose with Ale, and Allyson.

Salute to Safety

This month, in honor of Autism Awareness Month, May Institute's Southeast Regional Autism Center (SERAC) in Columbus, Ga., will team up with the local police and fire departments, and local safety organizations, to present the second annual "Salute to Safety." This event combines fun and games with important safety information for families and "first responders" alike. It provides an opportunity for police officers, fire fighters, and emergency medical service (EMS) personnel to interact with children with special needs.

"We give these kids the opportunity to meet police, fire fighters, and EMS workers in a friendly and fun environment," explains Amy Bontrager, Community Outreach Coordinator for the Southeast Regional Autism Center. "This makes it more likely that they will react positively to first responders in the future."

The event also exposes first responders to some of the sensory issues and behaviors displayed by many children with autism spectrum disorders and other special needs. "Then, when they come into contact with these children in the community," Bontrager continues, "they will respond more effectively."

For more information, contact the Southeast Regional Autism Center at 706-571-7771.

"stop" and "come here"), waiting (e.g. waiting before going outside, etc.), and learning personal information.

Teaching Personal Information

Behavior analysts often include this safety-related skill in a child's in-home behavioral goals. It is very important that children like Ale, who impulsively run or wander away, learn some basic personal information such as their parents' names and phone numbers. Then, if they get lost, they can tell someone who their parents are and how to contact them.

With Ale, Marianne and Whitney started by making sure he could tell people his name. "Then it was his first name and last name," says Jose. "Then my name, then his address, then the phone number, then his birthday and his age," he continues. "Now they're about to start adding in the name of the school, his teacher's name, his city, and his brother's and sister's names."

When teaching a child to memorize his phone number, behavior analysts may use a visual prompt at first, so the child can identify each of the numbers on a piece of paper when asked, "What is your phone number?" Again, depending on the child's preferences, a reward

can be provided immediately after he responds correctly. Once the child is consistently saying his phone number with the visual prompt, the numbers can be "faded out" (i.e., take one number away, then two, three, and so on). The numbers will continue to be removed until the child can give the number without the visual prompt, when asked, "What is your phone number?"

Teaching children with ASD who are non-verbal how to communicate important personal information poses additional challenges. Some may be able to carry a card that has their name, address, hometown, telephone number, and parents' names on it, but this may not be feasible for all children. This information can also be conveyed through the use of safety temporary tattoos or stickers that a child can wear out

in public. This eliminates the need to regularly confirm the child still has the card with him.

Occasionally, children are so excited about memorizing their phone number or address that they will recite it to anyone who will listen. It is important to teach them that we only share personal information in certain situations, and with certain people.

Wandering and "Stranger Danger"

A big concern for parents of children with special needs who are inclined to run away or wander is that they may become lost or encounter an adult who might try to harm rather than help them.

For Ale, strangers do not pose a danger because he is very wary of people he does not know and will scream if a stranger tries to talk to him. And, at this point, Jose and Johan are not worried about Ale running or wandering away when he is inside their house. "That's not a concern yet," says Jose, "but there is the possibility that he might start opening doors later on. Both his therapists have impressed upon him that, if he wants to go out, he must ask an adult to open the door."

"If parents have children with ASD who are able to open doors and are at risk for wandering away and possibly getting lost or hurt, they might want to consult a professional who specializes in both the behavioral treatment of ASD and the behavioral treatment for wandering," advises Susan M. Wilczynski, Ph.D., BCBA, Executive Director of the National Autism Center. "This professional will be able to conduct a thorough functional analysis to determine the reason for the child's actions." According to Dr.

Serving Military Families Across the Country

May Institute's Regional Autism Centers in Georgia, Massachusetts, and North Carolina are dedicated to meeting the immediate and pressing need for services for children with autism spectrum disorders in all branches of the military – Army, Marines, Navy, Air Force, and Coast Guard. Additional sites in Connecticut, Florida, and California also offer services for military families. The Institute is planning to further expand its ability to serve military families through new Centers in Texas, California, and Hawaii, all in close proximity to key military installations.

Wilczynski, there are four primary reasons why a child might run away or wander: to gain access to desirable items or activities; to get attention; to avoid undesirable situations; or because they require a different level of sensory stimulation than is currently available (the child might feel the need to run after sitting for a long period of time, for example).

After the reason for the running away or wandering has been determined, an individualized treatment program can be developed to address the behavior. "This program should outline specific actions that parents will take if a child runs away or wanders," Dr. Wilczynski advises. "It should include suggestions for how they might re-structure the environment so the child is less likely to run away." At the same time, both verbal and nonverbal children should be taught successful strategies for getting their needs met. "For example," continues Dr. Wilczynski, "it is best to teach a child to request a visit to the local park if his reason for running away is to spend time in that location."

Despite the best efforts of families and professionals, some children may continue to run and wander away. When that is the case, parents may consider additional precautions throughout the home, as well as safety devices or products. Some families invest in personal tracking devices or systems that can help to locate their child if he runs or wanders away.

It is important that children who are at risk for wandering away and encountering strangers be taught to identify men and women in uniform such as police officers or fire fighters – or even store clerks with identification badges – who will be most likely to offer assistance if they are lost. When possible, it is equally important to share relevant information with local safety personnel, and to educate these individuals about the unique needs of these children.

Keeping children with ASD or other developmental disorders safe at home, school, and in the community is a tremendous responsibility and challenge

for military and civilian families throughout the country. Fortunately, families like Ale's have discovered that there are skilled behavior analysts, dedicated school personnel, and caring "community helpers" ready to provide support and guidance every step of the way. •

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analyst. Anne served as Clinical Director and Senior Behavior Analyst at May Institute's Southeast Regional Autism Center outside Fort Benning, Ga., before moving to Camp Lejeune to open the Institute's second Center last year. The Southeast Regional Autism Center in North Carolina serves Marine Corps families with children with autism.

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RESOURCE LIST

Autism Society of America's "Safe and Sound" campaign (www.autismsociety.org)

National Autism Association's "Autism Safety Toolkit" (www.nationalautismassociation.org)

Safety Net Source, information for caregivers of people at risk of wandering, provided by LoJack (safetynetsource.com)

Georgia Department of Community Health, Emergency Medical Services and Trauma, STAR Kids Program (www.ems.ga.gov, 404-679-0547 or 706-321-6150)

Call For Stories!

Exceptional Parent magazine wants to help you share your stories. We are currently soliciting articles for inclusion in the **military section** of EP in the following areas.

- **Stress Management:** We are looking for contributors who can discuss how they manage **stress in dealing with the military health care system, their child's disabilities, and deployments.**
- **Mental Health Issues:** We are seeking information about how military families have coped with a diagnosis of **childhood depression related to having a military parent.** Also, we want to know **how veterans deal with the depression associated with Post Traumatic Stress Disorder (PTSD) and other war injuries.** Additionally, we are soliciting stories and articles about **families coping with a diagnosis of moderate to severe anxiety.** Do veterans face anxiety as they encounter treatment for injuries and how does the military help them cope with the anxiety of continued and prolonged treatments?
- **Traumatic Brain Injuries (TBI):** Throughout the year, we plan to continue to tell the stories of **how Wounded Warriors and their families overcome injuries and cope with the lingering issues of TBI.**
- **Assistive Technology:** In July, we would like to find military contributors who will tell stories of **how assistive technology has helped a military child or adult** with disabilities in their daily lives.
- **Prosthetics:** With the current conflicts in Iraq and Afghanistan, many of our servicemembers are returning home with life-changing injuries. We are asking these brave individuals to share their stories of how **the use of prosthetics and other aids** are helping them recover from these injuries and transition to different ways of living at home.
- **The Military Child and War:** Are you a returning vet (or the spouse to one) who has a war-related disability and a young child? Explaining your injury and **"coming home different"** can be a difficult process for a military family. Please share your story on dealing with this aspect of military family life.
- **Assistance Animals:** The May issue will include stories from contributors who have assistance animals in their families and **how those animals have contributed to the well-being of their child, veteran, and/or family.**
- **Sports and Recreation:** In June, we would like to find military contributors who utilize **Sports and Recreational activities for individuals with special needs.**

For more information, deadlines, and questions about these and other story ideas, please contact EP's Military Editor at militaryeditor@eparent.com.