



FAMILY & COMMUNITY



Riley, who is a "Daddy's girl," shares a quiet moment with Alan before attending a wedding.

TEAM RILEY

Joining Forces to Help a Child with Rett Syndrome Find Her Voice

By Jade Lewis, M.Ed., BCBA
and Patricia Ladew

In the April 2011 issue of EP Magazine, readers met Riley, daughter of Army sergeant Alan and Jessica Steventon of Fort Campbell, Ky. ("A Full Plate: Helping a Child With Rett Syndrome Thrive and Grow"). Riley, diagnosed with Rett syndrome at 26 months, weighed only 28 pounds at age four. The article focused on the therapy she was receiving to help her eat more and gain weight.

Rett syndrome is a rare neurodevelopmental disability that is currently considered an autism spectrum disorder (ASD). Unlike autism, Rett syndrome almost exclusively affects girls. It occurs in one of every 10,000 to 23,000 female births. In addition to challenges with eating and digestion, girls with Rett syndrome also have problems with brain function that affect learning, speech, sensory sensations, mood, movement, breathing, and cardiac function.

Shortly after that article was published, Riley underwent surgery to have a gastrostomy tube (g-tube) inserted into her body to provide the nutrients and hydration she needed. Since then, she has grown four-and-a-half inches and gained 14 pounds. "She's right where she should be now," says Jessica.

As Riley grew and gained weight, she developed the strength to do many things she had been unable to do before, such as sit down unassisted (a skill that has helped her as she works on her toileting skills). And because she is "pump fed" throughout the night, she is sleeping better – and so are her parents.

"It is amazing," says Jessica. "It's made such a difference in our lives. As a parent, you struggle making the decision about the feeding tube. It's such a difficult decision. And then, after you do it, you think, 'Why didn't we do this before?' Because you can see how it has made a huge difference in Riley's life."

Another important change in the Steventons' lives since that first article is that Alan returned home safe and sound after his third tour of duty in Afghanistan.

Focusing on Communication

As Riley began to thrive physically, her parents and therapists turned their focus from her food intake to helping her improve her communication skills. They considered a number of different communication aids, including the Picture Exchange Communication System (PECS), a form of augmentative and alternative communication for children with special needs. But PECS requires a child to manipulate pictures attached to a board, something that is nearly impossible for Riley, who has limited fine and gross motor skills.

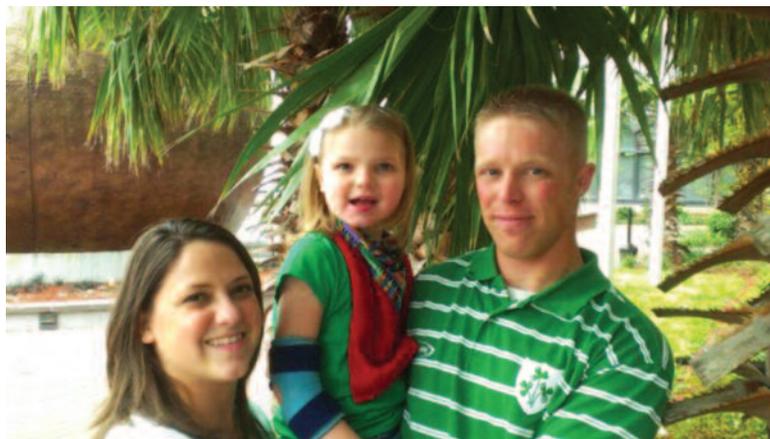
Before she had her feeding tube, Riley, who is non-verbal, used a communication device. When she wanted to eat or drink, she would press pictures that showed her eating or drinking. While this device helped improve her requesting skills, it didn't help her communicate specific preferences, and it was difficult for her to press the pictures without help.

"It's challenging because Riley's gross and fine motor skills are problematic," says Christina Giuliano, M.S., BCBA, a board certified behavior analyst and Clinical and Program Director of May Institute's Center for Autism Spectrum Disorders in Clarksville, Tenn. Christina led the team that provided applied behavior analysis (ABA) services [see related sidebar] to Riley while the Steventons were stationed at Fort Campbell. "We had to think long-term with Riley. Because she has Rett's, we know that she may lose motor skills in the future."

But one skill that Riley will most likely retain is her ability to use her eyes to focus on and "gaze" at items she wants. "We didn't have to teach her that skill,"

says Christina. "When she was younger, she learned how to communicate by staring at objects or pictures. When she really wanted something, she would stare at it for a long time – like a package of crackers in the cupboard."

Riley's parents and therapists agreed that "eye gaze" was her best form of communication. So they went to work developing a system to help her communicate her needs and wants by using her eyes. "We started 'low tech,' using picture cards on a board," Christina explains. "When she would look to the upper left, we knew that meant she was hungry because the icon in the upper left was for eating."



Jessica, Riley, and Alan enjoy a sunny afternoon outdoors.

RILEY LEARNED HOW TO SCAN A NUMBER OF PICTURES BEFORE MAKING HER CHOICE, & THEN FOCUS ON ONE PICTURE LONG ENOUGH FOR THE COMPUTER TO "READ" HER GAZE.

Next, they put together a multi-section binder of pictures. The first section had pictures of Riley's main choices – eating, drinking, or going outside, for example. If she gazed at the picture for eating, Jessica or Christina would turn to the section that had pictures of her food choices. She could make her choice by staring at a picture of a specific food item.

A Voice For Riley

Christina recorded data on Riley's success with this method of communication. She worked with speech therapists at Vanderbilt University to build a case to present to TRICARE, the Steventons' military insurance provider. The goal was to convince TRICARE to help cover the cost of a special eye gaze computer system that would help Riley communicate by "reading" what her eyes were focusing on and then verbalizing what she wanted.

Their efforts were successful and TRICARE approved the purchase of the eye gaze device. Then Riley's therapy team began to work on how to help her use this powerful new tool. One of the skills she needed to learn was how to scan a number of pictures before making her choice, and then focusing on one picture long enough for the computer to "read" her gaze. "We did that by starting with just one picture so she would learn that if she looked at it long enough, she would get whatever that picture represented," explains Christina.

Riley's favorite "reinforcer," or reward, is listening to music by Taylor Swift. "When she stared at a picture of a music symbol, we would put the music on," Christina says. "After a minute, we would turn it off. As soon as Riley looked at the picture of "music" again, we would turn Taylor Swift back on."

Building on this success, they were able to create a multi-level process to communicate by using the new computer system. For example, Riley could "say" that she was hungry by staring at a food icon on the computer screen. Then a second screen would show her pictures of her food choices. By scanning the choices and then focusing her gaze on one item, she could make her selection. After she could successfully complete a two-level process, the team added a third screen that gave her the opportunity to "comment" on her snack by staring

United States Military Section

at icons that said “yummy,” “more, please,” or “that’s disgusting!”

“Then we started using the eye gaze system to work on educational goals such as matching real objects with icons on the screen,” says Christina. “We also worked on receptive identification (identifying an object when the name is spoken out loud) of basic numbers and letters and functional items in the home, such as “bed” and “toilet.”

The eye gaze system worked so well for Riley that the Department of Defense (DOD) approved the purchase of an identical eye gaze computer for her DOD classroom.

“We were delighted,” says Jessica. “The new system gave Riley an opportunity to have a voice. It’s something we have always wanted for her.”

The Move to Fort Stewart

Riley continued to work with Christina and, later, with James Kretzer, BCBA, another board certified behavior analyst from the May Center in Clarksville. At the same time, she was receiving physical, occupational, and speech and language therapy, as well as music and horseback riding therapy to improve gross motor skills. Jessica and Alan were feeling very pleased with the steady progress Riley was making. But, just when everything seemed to be going smoothly, they were notified that Alan was being reassigned to Fort Stewart in southeast Georgia.

Jessica and Alan wondered what this would mean for Riley and her carefully coordinated therapeutic schedule.

Fortunately, May Institute serves military families at more than 20 installations throughout the country. Its Center in Savannah, Ga., serves families stationed at Fort Stewart.

“Military families can get their orders anywhere from one to six months before they have to report. So as soon as we heard

the Steventons’ news, James and I started working with our Georgia colleagues, including behavior analyst Brandi Hays, to plan for Riley’s transition,” says Christina.

Brandi was familiar with Riley’s case because May Institute clinicians from across the country “meet” regularly via videoconferencing to discuss challenging cases, share research findings, and conduct trainings. And because all May Institute clinicians receive the same training and use the same documentation systems, moving from one Center to another can be relatively seamless for military families whose children are receiving services from May Center behavior analysts.

“The comfort of knowing that we weren’t starting from scratch when we moved was very nice,” says Jessica. “Her previous and present therapists collaborate as a team now. It’s wonderful because they have all spoken with each other and they started planning way in advance of the move so there would be as little ‘lapse time’ as possible when we got here. That’s so reassuring.”



Brandi Hays, a May Institute behavior analyst in Georgia, helps Riley use the eye gaze system.

It Takes a Village

As we go to press, the Steventon family is settling into their new home on Fort Stewart and preparing to set up a new “Team Riley.” Brandi, the first member of the team, has consulted with Christina and James about Riley, met with the Steventon family several times, and is in the process of conducting a reassessment on Riley.

Unfortunately, but not unexpectedly for a child with Rett syndrome, Riley has had some regression in her skills over the past month, while the family was in transition. She has lost some ground with her eye gaze skills and has been exhibiting some challenging behaviors such as

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SERVING MILITARY FAMILIES ACROSS THE COUNTRY

May Institute’s Centers for Autism Spectrum Disorders (ASD) in Georgia, North Carolina, Tennessee/Kentucky, Florida, Virginia, New England, and

(coming soon) New Jersey 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.

“mouthing” (or gently biting her hands and upper arms), grinding her teeth, and holding her breath.

Brandi is already addressing these behaviors and studying the eye gaze treatment plan that was developed and implemented by Christina and James. The good news is that Riley’s DOD school in Kentucky is sending the eye gaze device it purchased for Riley to her new DOD school in Georgia. That will ensure consistency for Riley as she works to regain her eye gaze skills at home and at school.

“I anticipate that we will get back into the swing of therapy sessions three days a week. That will help Riley with her proficiency and speed and accuracy of using her eye gaze communication device,” says Jessica. “I also look forward to getting other therapists and her new teachers at school on board to help us work with Riley.

“The May Center has been fantastic at facilitating collaboration between all of our therapists so we could all be on the same page and all work together for the same goals for Riley,” adds Jessica. “It truly does take a village to raise a child with special needs because you need the help of a community to do it. And it really has been a village of people who have been helping us raise our daughter.”

Daddy’s Girl

As the co-captains of “Team Riley,” Jessica and Alan have always been very involved parents. Even when Alan was in Afghanistan, he and Jessica would consult regularly on important decisions that had to be made about Riley’s treatment. Now that he’s home, he’s playing an even bigger role in Riley’s life.

“She is such a Daddy’s girl,” says Jessica. “She loves that man so much and he is so good with her. He wants to be the one

who changes her into her pajamas at night. He wants to be the one who feeds her dinner. He wants to spend that time with her. He started going back to school, but doesn’t do his homework until after Riley goes to bed. That way, when he comes home from work, every moment he has is spent with her until she goes to sleep. We don’t know when he’s going to be deployed next. So every moment that he is home is dedicated to Riley.



Christina Giuliano, Riley’s former behavior analyst in Tennessee, reads to her during one of their in-home sessions.

Educating the World

“It’s our job to help Riley through this life and to help her communicate,” Jessica adds. “And it’s our job to work toward treatments that are successful for Rett syndrome. I also think that it’s our job to educate people about Rett syndrome. It’s not just about our daughter. It’s about a whole community of Rett syndrome families who needs and want this. Someone once said, ‘I thought I would have to teach my daughter about the world. It turns out I have to teach the world about my daughter.’ That’s how I feel.

“Our biggest goal for Riley is that she has the most fulfilling, healthy, and happy life that she can. That she gets to teach the world about Rett syndrome and about herself. And that she truly helps to create a world of empathy instead a world of sympathy, where people pity you instead of being there to understand and encourage you.” •

About the Authors:

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APPLIED BEHAVIOR ANALYSIS

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.

ABA has been endorsed by the National Institutes of Health and identified by the Surgeon General of the

United States as the most effective way to treat ASD. According to the National Autism Center’s National Standards Report (2009), data collected through hundreds of studies indicate that ABA is a highly effective method to teach children and adolescents with ASD.