

Autism's Challenges



Combating Stress on the Home Front

By Alan Harchik, PhD, BCBA and Lauren Solotar, PhD

According to a 2007 report from the Centers for Disease Control and Prevention (CDC), about one in 150 children in the United States has an autism spectrum disorder (ASD) that causes difficulty with behavior, communication, learning, and social interaction. ASD is more common than cerebral palsy, Down syndrome, pediatric cancer, diabetes, and AIDS combined. Autism in particular is on the rise and is now the second most common developmental disability after mental retardation.

When a child is diagnosed

with autism, every member of the family is affected. While every family's experience is unique, there are common challenges that most families face. These include dealing with the diagnosis, choosing the best treatment options, and building a strong and supportive family structure.

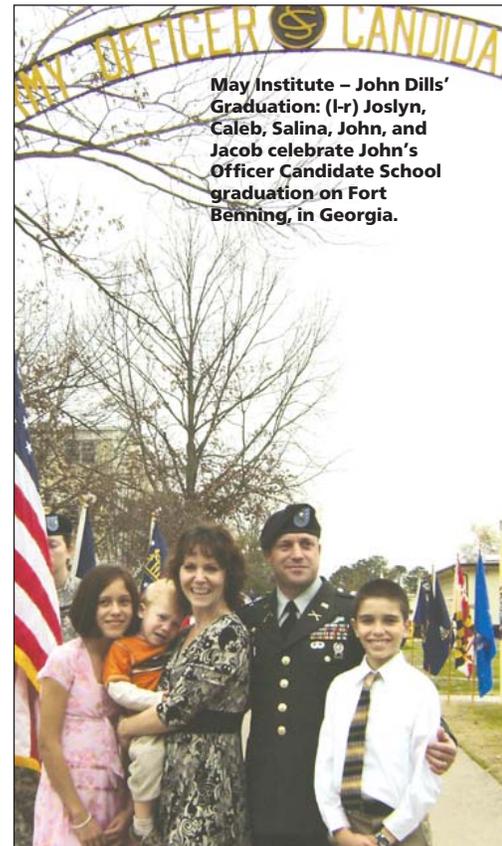
For military families, the difficulties presented by these challenges are often exacerbated by the lack of proximity to family and support networks, frequent relocation, school and training schedules, and more. Managing the stress that accompanies these challenges is critical to a family's long-term health and well-being.

Diagnosis and Early Intervention: Keys to Success

Salina Dills, who lives on Fort Benning in Georgia, is awaiting a diagnosis for her two-and-a-half-year-old son, Caleb. His primary symptom is delayed speech, something Salina noticed more than a year ago. She expressed her strong concern to Caleb's pediatrician at his two-year checkup, and Caleb recent-

ly had a comprehensive evaluation. Waiting for a diagnosis has placed a lot of stress on the family.

"This could be our life," says Salina, "and what does that mean for us? What does that mean for our son? Is he going to have this lifelong struggle? Is he going to be one of those kids who can't ever go to a regular classroom and have ordinary relationships? What will his quality of life be? What do you do? How do you do it? All of these questions swirl through your mind... it is overwhelming."



May Institute – John Dills' Graduation: (l-r) Joslyn, Caleb, Salina, John, and Jacob celebrate John's Officer Candidate School graduation on Fort Benning, in Georgia.



May Institute – Dills Family: The Dills family poses for a family photo: (l-r) Caleb, Salina, Jacob, Joslyn, and John.

Could My Child Have Autism?

Some of the first signs that a child might not be developing typically include a lack of eye contact, no pointing or gesturing by 12 months of age, no babbling or no inflection in voice tone when babbling, no use of words by 12 months, no use of phrases of two or more words by two years, no make-believe play by two years, and a loss of language and social skills.

These signs do not mean that a child has autism, but they are an indication that parents should seek further information from their family physician or pediatrician. Most pediatricians can conduct an initial screening for autism. If needed, families should then be referred to an expert in the field for a comprehensive diagnostic evaluation.

Taking Action

Suspecting that your child is not developing in an age-appropriate manner can be very frightening and stressful for parents and families. It is important to share your concerns with a physician, therapist, or early education specialist. Make sure your concerns are heard and your questions answered. Advocating for your child to get an appropriate assessment is critical.

Accessing information and taking action are two steps that can help you manage anxiety. During this waiting period, it may be helpful to speak to other parents who have gone through this process. It can help you prepare to hear difficult information and think about different options that will fit into your family's lifestyle.

If your child does have autism, it is crucial to identify it as early as possible so treatment and intervention can begin. Although evidence shows that intensive early intervention during the preschool years results in the best outcomes, it is estimated that only half of the children with ASD are diagnosed before they enter kindergarten.

Acknowledging the need for earlier diagnosis, the American Academy of Pediatrics (AAP) recently released two reports to help pediatricians recognize ASD earlier and guide families to effective interventions. (These reports and an autism checklist for parents are available at <http://www.aap.org>.)

Dealing With a Diagnosis

If your child is diagnosed with a disability, give yourself time to absorb this life-changing information. You will need to adjust your hopes, wishes, and dreams for your child and your family. Talking to other families, sharing information, accessing all of the resources available, and developing both a formal and informal support network are all helpful in managing stress. For families living on military bases, spouses' networks and neighborhood groups can provide critical support.

Katherine Bray of May Institute's Southeast Regional Autism Center in Columbus, Georgia, also lives on Fort Benning, and is the parent of a child with ASD. She recently shared a story about a neighbor who came to her door in tears, having just received a similar diagnosis for her young son. A mutual friend suggested to the mother that she talk to Katherine. "Word of mouth on a military base can connect families to other families," she said. "My neighbor didn't know how to begin to absorb the information she had received. We talked for a long time, and she is now setting up essential services for her son."

Support groups are also useful because they decrease your sense of isolation and increase your ability to cope. Groups offer opportunities to

share stories about finding effective interventions, managing difficult situations, and moving forward with your life.

Once a diagnosis is confirmed, it is helpful to learn as much as you can about the disorder. Obtaining research information about ASD and treatments from the Internet, conferences, and reading materials help families manage their anxiety about the diagnosis. Be sure to share information with siblings, family, and friends so people close to you can learn what you are learning and provide support and feedback.

Choosing Effective Treatments

How can parents of children who have been diagnosed with autism choose the best treatment for their children? Recognizing that some treatments have evidence showing their effectiveness, and that others do not, is an important part of this decision.

Many educational methods for children with autism are based on good research that has been tested and shown to be effective. One of these methods is applied behavior analysis (ABA). Hundreds of scientific studies have shown that ABA is the most effective method to teach children and adolescents with autism and other developmental disabilities. ABA facilitates



May Institute – Dill Children Fun:
Caleb (c) enjoys fun times with
sister Joslyn (l) and brother Jacob (r)

United States Military Section

the development of language, social interactions, and independent living by applying basic behavioral practices – positive reinforcement, teaching in small steps, prompting, and repeated practice. In addition to building critical skills, ABA can also help reduce everyday social problems and serious behavior disorders.

Unfortunately, the prevalence of methods that have no evidence of effectiveness is widespread. You see it every day in advertisements, infomercials, and treatment options offered to parents of children with autism. Extraordinary claims are made that are unsupported by objective evidence. Risks to children are minimized or denied.

It can be very stressful choosing the “best” treatment for your child, and more so if you are on your own. Contradictory information makes this even more difficult, especially when dealing with a new diagnosis. Read the research and learn as much as you can about what treatments are supported by the most evidence. Ask questions. Talk to your providers about recommended treatments and talk to other families who have gone through a similar process.

“ABA has been the best method for Gabe,” says Jodi Davidson, a military mother of a five-year-old with autism. “He progressed by leaps and bounds with ABA. Doctors didn’t think he would ever speak, but, with the help of ABA, he started talking at age four.”

Building Support Through Family

As any family would adapt and respond to the twists and turns of childhood, so too does the family of a child with autism. But families of children and adolescents with autism must face some unique challenges and stressors that those of typically developing youngsters do not.

One of the best ways to manage stress is to strive to maintain balance in your life and family. Designate

time to take care of your other children, your relationship, and yourself.

Siblings can play an important role in the life of a child with autism. Include siblings throughout all life stages and encourage them to develop independent relationships with their brothers and sisters who have autism. There are many books for and about siblings of children with special needs, and many communities offer support groups.

Managing Stress to Maintain Balance

Taking care of a child with a disability puts a lot of stress on a relationship – it is important to discuss your feelings and thoughts about treatment with your spouse. Each of you may need support in different ways, and it is important to communicate about your needs. If your spouse is overseas, it is even more critical to maintain a constant dialogue through e-mail, text messaging, or phone calls about the progress your child is making, how it has impacted the rest of the family, and how to support one another.

It will take a significant amount of time and energy to develop and sustain appropriate services for your child with autism. For the spouse who is living on the installation, it is helpful to develop a support network.

Jodi Davidson, Gabe’s mother, talks about the challenges she faces when husband Christopher is deployed for six months at a time. “It’s very stressful for me, the parent left behind. It’s a very long and hard time when he’s gone,” she shares. Christopher acknowledges the burden. “My heart goes out to Jodi,” he says. “She is such a strong woman. When I’m gone, she takes on both our roles and does everything. I don’t think I would be able to do it.”

Jodi finds ways to support Gabe and find balance. “Children with autism like consistency, so it’s very important to keep life as normal as possible when a spouse is deployed,”

About May Institute

May Institute is a nonprofit organization that provides educational, rehabilitative, and behavioral healthcare services to individuals with autism and other developmental disabilities, brain injury, mental illness, and other behavioral healthcare needs. The Institute also provides training and consultation services to professionals, organizations, and public school systems.

Since its founding over 50 years ago, May Institute has evolved into an award-winning national network that serves over 25,000 individuals and their families annually. With corporate headquarters in Randolph, Massachusetts, the Institute operates more than 200 service locations in the Northeast, Mid-Atlantic, Southeast, Midwest, and on the West Coast. Six May Institute schools serve children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. A seventh school serves children and adolescents with brain injury.

An active center of research and training, the Institute maintains affiliations with more than forty universities, hospitals, and human service agencies worldwide.

May Institute is the first nonprofit human services organization in the country to receive top national honors from the Society for the Advancement of Behavior Analysis (SABA) and the Association for Behavioral and Cognitive Therapies (ABCT). The Institute received the 2005 Outstanding Training Program Award from ABCT and the 2007 Award for Enduring Programmatic Contributions in Behavior Analysis from SABA.

In 2005, May Institute sponsored the initial development of the National Autism Center, a groundbreaking nonprofit organization dedicated to supporting effective, evidence-based treatment approaches for autism, and to providing direction to families, practitioners, organizations, policy-makers, and funders. Together, May Institute and the National Autism Center are committed to identifying and applying universal standards for the treatment of autism and to providing care and hope to families throughout the country.

she says. "It's good to get support from other families who have children with autism or from friends. Sometimes, you just need a short break."

During periods of high stress, having a range of accessible activities can help you decompress. Jodi finds that short breaks help her find balance. Think about activities that might help you relax and feel good. Options include:

- Exercise
- Take a time-out for yourself – visit with a friend or curl up with a good book
- Call a good friend or close family member
- Learn how to do yoga
- Pamper yourself—take a long bath or get a massage
- Go out to dinner or on a date with your spouse or a friend
- Organize respite care

- If you are religious, turn to your faith and church friends for comfort
- Keep a journal to write down your thoughts and feelings
- Develop a new hobby
- Listen to music

Attending to your own needs, maintaining an awareness of the needs of each member of the family, and putting systems in place to support the family will help lessen disruptions, keep channels of communication open and create an environment that is healthy, loving, and supportive for everyone, including the child with autism.

With effort and communication, families can get through the challenging times and come out stronger in the end. "The last time I returned home from being deployed," Christopher remembers, "Gabe hugged me and wouldn't let go for about an hour and a half. I knew he still loved me just as much as when I left." •

Alan Harchik, PhD, BCBA, is May Institute's Chief Operating Officer, a licensed teacher of children with disabilities, Board Certified Behavior Analyst, and a member of the leadership team of the National Autism Center. Dr. Harchik has extensive expertise in the areas of autism and applied behavior analysis and has been published in a variety of professional journals. He writes a monthly column on autism and other disabilities for *The Republican* newspaper in West Springfield, Massachusetts and serves as an expert consultant for the Civil Rights Division of the United States Department of Justice.

Lauren Solotar, PhD, is May Institute's Chief Psychologist and Senior Vice President of Clinical Services. Dr. Solotar is an expert in cognitive and dialectical behavior therapies, and specializes in anxiety disorders. She has extensive experience working with children and adolescents. Her research has been published in professional journals, including *Behavior Therapy* and *Journal of Consulting and Clinical Psychology*, and she has written a chapter in the *Child Behavior Therapy Casebook*.

NOTE: Drs. Harchik and Solotar wrote all of the sidebars in addition to the main article.

May Institute Locations

May Institute operates more than 200 programs across the country. A list of its corporate and regional offices follows:

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