

May Institute Responding to the Critical Need for Autism Services

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



Dr. Walter P. Christian, PhD, ABPP, May Institute's President and CEO, visits with the integrated preschool classroom in one of the Institute's schools for children with autism and other developmental disabilities.

As May Institute

has evolved over the past five decades into a national organization with more than 200 program locations, we have been guided by our mission of helping families navigate the complex world of autism and related disabilities. Earlier this year, that mission led us to Columbus, Georgia, where we opened our newest program, taking resources to families stationed at Fort Benning, home to a military community of more than 100,000.

In 1955, when Dr. Jacques and Marie-Anne May opened the doors to what would become May Institute's first school for children with autism, their twin boys were among its first students. The Mays were parents, but they were also visionaries whose dream was to create a place that would take "a total and complete involvement with the child...a special sensitivity to the needs of others...and an extraordinary kind of imagination."

Jacques and Marie-Anne understood that their boys' journey with autism would include unexpected turns and unfamiliar territory. Although that journey began in the early 1950s, when very little was known about autism, the challenges the May family faced resonate today with families across the country and beyond.

Military families are often confronted with a very particular set of challenges as they navigate that journey with their children. (See accompanying article, "One Family's Story" on page 51.)

Autism, a neurological disability that causes difficulty with behavior, communication, learning, and social interaction, can create enormous stress on a family – stress that is magnified when one spouse is away for extended periods of time, when trans-

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One Family's Story

Major Bill Nelson and his wife, Karen, are very familiar with the challenges that confront military families who have a child with autism. They were stationed in Korea when they began thinking something might be wrong with their son. "We had our suspicions when Peyton was two and a half," says Karen. "We went to see a developmental pediatrician who recommended early intervention services, which Peyton got during a medical visit to Tripler Hospital in Hawaii. He wasn't officially diagnosed with ASD until we moved to Fort Campbell, Kentucky, when he was three years old."

By this time, two physicians had recommended speech and occupational therapy, but the Nelsons discovered that finding professionals who could provide these services at a military installation was nearly impossible. "I had to search to find a speech therapist at Fort Campbell," Karen says.

"Peyton saw an occupational therapist there, too. But those were the only services we could get for a while."

Doctors had also recommended applied behavior analysis (ABA) therapy, but there were no ABA therapists to be found at Fort Campbell. When the Nelsons moved to Fort Benning in Columbus, Georgia, Karen continued her search.

Karen found an ABA therapist through a chance encounter with a fellow officer's wife whose son has a developmental disability. The boy was receiving in-home ABA services from Jade Lewis, BS, BCABA (Board Certified Associate Behavior Analyst), a May Institute behavior therapist who commuted between Atlanta and Columbus, a round-trip distance of about 200 miles. Karen and Bill were thrilled when Jade, who is now an employee of the new Southeast Regional Autism Center, moved to Columbus and started to work with Peyton.

ABA – The Missing Link

"ABA was the missing link for us," says Karen. "Jade rocked our world. She is what we needed. Occupational and speech therapy are great, but we needed Peyton to behave and cooperate," she explains.

Seven-year-old Peyton is now a second-grader at Lloyd Elementary School, which is part of the Department of Defense school system at Fort Benning. He is in a "life skills" classroom, but joins his typically developing peers for music, art, physical education, and lunch.

The school has been very receptive to Jade coming in and consulting with teachers on how to work with Peyton's behaviors. "She converses with his teacher and is on his IEP (Individualized Education Program) team," Karen says. "Her job is to make his behaviors better so the teachers can teach him."



Karen, Peyton, and Bill celebrating Christmas together.

A System for Success

Using the principles of ABA, Jade is also helping Peyton and his parents develop a system to get his homework done. "We needed a system," says Karen. "We weren't being consistent and sometimes it got ugly. He would have meltdowns."

Peyton's homework system works like this: He gets to watch his favorite cartoon DVD for a few minutes. When a pre-set timer goes off, he sits down and starts his homework. He chooses which page of homework to start with and which pen or pencil he wants to use. Then he gets a small treat (a tiny piece of candy). When he completes a page, he may watch a few more minutes of his cartoon. When the timer goes off, the process is repeated. "It's worked beautifully," says Karen. "He's really done well."

Jade explains how ABA therapy is truly a partnership between family and therapist. "I couldn't have made this much progress with Peyton on my own," she says. "His parents have been supporting everything we have been doing with him. I just gave them the tools they needed and they ran with it."

Like loving, supportive parents everywhere, Karen and Bill Nelson have hopes and dreams for their child's future success and happiness. "I'm hoping Peyton can be mainstreamed as much as possible," says Karen. "He's very smart. He has lots of potential."



Jade Lewis, May Institute behavior therapist, works one-on-one with Peyton in his home.



Peyton and his mother, Karen, spend time together reading.

The May Institute

fers create abrupt changes in daily routines, and, most of all, when effective services are not easily accessible.

A Personal Perspective

For May Institute President and CEO, Walter P. Christian, PhD, ABPP, who is largely responsible for the exponential growth of the organization over the past 30 years, opening the Southeast Regional Autism Center in close proximity to Fort Benning, was both a personal and a professional decision.

Christian is well acquainted with life on military bases and with the challenges that families often face when trying to access services for their children with special needs.

His daughter, Katherine, and her family have lived on various bases over the past 10 years and are currently stationed at Fort Benning. When Christian's grandson was diagnosed with a disability several years ago, the young boy began receiving services from May Institute's Atlanta office, about 100 miles away. His services, like all those provided by the Institute, are based on the principles of applied behavior analysis (ABA) – the most effective method to teach children and adolescents with autism and other developmental disabilities. (See accompanying sidebar to the right for more about ABA.)

Helping Families at Fort Benning

Well aware of the growing number of children being diagnosed with Autism Spectrum Disorder (ASD) throughout the country, Christian recognized that there would probably be a significant number of children on the installation with autism or other related disabilities who could benefit from ABA.

"It quickly became clear to us that the types of services military families needed weren't available to them in their community," Christian said.



"Families were willing to travel long distances to get care, and the need for ABA services was overwhelming."

That's when May Institute stepped in. For the past five years, behavior consultants from the Atlanta office have been providing home-based services to military families stationed on Fort Benning or in the surrounding Columbus area, traveling back and forth as needed.

Earlier this year, the Institute made the decision to expand its reach to better support Fort Benning families affected by ASD. The recent opening of the Southeast Regional Autism Center

in Columbus finally brought resources directly into the community, with consultants providing services at the point of need, in local homes and schools.

"We offer screenings for children who may be exhibiting signs of ASD," said Christian. "A local presence allows us to provide training and education to physicians, teachers, and parents, as well as home-based therapy to children with autism and other developmental disabilities."

As this new center expands its operations, the goal is to provide services at other bases throughout the Southeast.

Applied Behavior Analysis: Effective and Individualized

Applied behavior analysis (ABA) is the treatment of choice for children with autism. It is a methodology, or framework, that applies scientific interventions to address behavioral needs.

What most attracts parents to a program of ABA are its positive and reinforcing tone, its strong focus on teaching new skills, the documentation of progress in reports and charts, its foundation in research, and the manner in which it is individualized for every child.

ABA helps with the development of language, social interactions, and independent living by applying basic behavioral practices – a positive reinforcement, teaching in small steps, prompting, and repeated practice. ABA can also help reduce both everyday social problems and serious behavior disorders.

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 has been endorsed by the National Institutes of Health (NIH) and the Association for Science in Autism Treatment (ASAT) and has been identified by the Surgeon General of the United States as the most effective way to treat autism.

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 40 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 (NAC), 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.

For information about May Institute programs and services, please visit the May Institute Web site, at www.mayinstitute.org. For additional information, call (800) 778-7601, or send an email to info@mayinstitute.org. To contact the May Institute's Southeast Regional Autism Center, call (706) 571-7771.

Looking to the Future

We know much more today than in 1955, when many people believed that emotionally cold or uncaring parents were responsible for their child's disability and when children were typically institutionalized for life. We know the critical importance of an early diagnosis and the benefits of early and intensive treatment.

We are hopeful that ongoing research efforts will one day unravel the mysteries of autism. And, in the meantime, we know that effective treatments for children and adults with ASD are available now, offering tremendous hope for meaningful and lasting improvements in their lives.

Christian and May Institute are

committed to bringing that hope to families throughout the country. With his dream of supporting military families now a reality in Columbus, he looks to the future. "I believe we have far surpassed Jacques and Marie-Anne's vision by creating a national network of programs that is, indeed, extraordinary," he said. "We will continue to meet the needs of families, and advance the care available for children with ASD. There is still much to be done." For information about May Institute programs and services, please visit the May Institute Web site, at <http://www.mayinstitute.org>.

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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.

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 nearly twenty years.

May Institute operates more than 200 programs across the country

Its corporate and regional offices are as follows:

May Institute Corporate Headquarters

- Randolph, Mass.

May Institute, Southeast Region

- Atlanta, GA
- Columbus, GA
- Orange Park, FL

May Institute, Northeast Region

- Yarmouthport, Mass.
- Fall River, Mass.
- West Springfield, Mass.
- Manchester, Conn.
- Freeport, Maine

May Institute, Midwest Region

- West Peoria, Ill.

May Institute, Mid-Atlantic Region

- Mount Holly, New Jersey

May Institute, West Coast Region

- Santa Cruz, Calif.