

Choosing Effective Treatments for Children with Autism

By Alan Harchik, PhD, BCBA, and Patricia Ladew

As the number of children diagnosed with autism spectrum disorders (ASDs) continues to skyrocket in both civilian and military families, so do the number of treatment options. Through the media and the Internet, parents of children with an ASD learn about many different types of procedures to treat autism and related disorders. Wanting to do everything possible for their sons and daughters, they will often try a number of different therapies and treatments.

After their son, Cameron, was diagnosed with autism at age three and a half, Army Master Sergeant Larry Carter and his wife, Christal, made it their mission to learn all they could about the best treatments for a child with autism. In the past four years, they have tried a number of different therapies with varying degrees of success.

"We talked to other parents, read books, researched on the Internet, took courses, attended conferences, and watched autism specials on TV," Christal told us during a recent interview. "It was quite a hodgepodge. There is no one resource for information about autism."

The Carters have worked with many different physicians, therapists, and consultants and have tried a variety of treatments—speech and occupational therapy, hippotherapy (using equine movement to address neurological functioning and sensory processing), aquatic therapy, chelation (using drugs to remove heavy metals from the



(l-r) The close-knit Carter family (Caitlyn, Larry, Christal, and Cameron) takes the opportunity to celebrate milestones together.

body), and biomedical therapies such as a gluten-free, casein-free (GFCF) diet and vitamin B12 injections—all in an effort to reduce Cameron's problem behaviors that included spitting, biting, kicking, scratching, and hair-pulling.

"We were doing so many things at one time; it's hard to know which did what," commented Christal. "You're scared to eliminate anything because you don't want to see regression."

When they needed help with Cameron's toilet training, they turned to a program that utilized applied behavior analysis (ABA), a methodology that relies on research-based interventions to address skill deficits and behavioral problems. After seeing the



Evaluating the Efficacy of Treatments for Autism Spectrum Disorders

By Susan M. Wilczynski, PhD, BCBA, and Leslie Sutro, PhD

When considering different treatment options for a child with autism, it's important to know if research has verified that a treatment is effective. There are lots of treatment options available, and while many of these may be supported by personal testimonials, many have not been shown to be effective by scientific studies. How do parents know what studies to look for and where to find them?

To be a savvy consumer, it is critical to determine which treatments are based on good science and which are based on pseudoscience. Good scientific studies involve:

- a solid research design
- strong tools for measuring change
- accurate identification that the children really have autism
- evidence that the treatment was provided accurately
- efforts to show the treatment produced positive outcomes over time or in different situations

Many studies do not meet these standards and are therefore not fully contributing to our knowledge about treatment effectiveness. Pseudoscientific studies involve information that sounds scientific, but in reality is not; they are not based on good scientific methods.

The Importance of Peer Review

One way to decide if a study is science or pseudoscience is to look at whether or not the study is a *peer-reviewed* study. The peer review process involves having other experts in the field read the study to determine if it is of good enough quality or makes an important enough contribution to the field to be published in a professional journal. Peer review is an important process because it ensures that a study meets the minimum acceptable standards of science.

Many public libraries have access to databases that contain links to peer-reviewed articles. University libraries and the Internet are also excellent resources for locating research databases, such as PsycINFO (<http://psycnet.apa.org/index.cfm?fa=search.advancedSearchForm>) and Medline/PubMed (<http://www.pubmed.gov>), which often contain a number of articles related to autism treatment. There are also certain Web sites for locating peer-reviewed articles (such as <http://www.scholar.google.com>).

The National Standards Report, a document that identifies the quality of research support for educational and behavioral treatments for school-aged



children and adolescents with autism spectrum disorders is expected to be released by August 2008 by the National Autism Center. This new resource will make it much easier for parents to determine the effectiveness of various treatments for autism.

Other Considerations

Scientific support is only a first step. There are several other key considerations when making treatment decisions. First, professional judgment should play a significant role. Even if a treatment has good scientific research support, it may only be applicable under certain conditions that may or may not be available. Second, the thoughts and opinions of parents and sometimes the children themselves should be taken into account. Third, ongoing treatment decisions should be based on data whenever possible. Data collection is crucial to determining if a child is responding positively to a particular treatment. Finally, the training and knowledge of those implementing a treatment should be considered. Once a treatment is chosen, the child's treatment team should determine what they need in terms of training, feedback, and materials in order to provide that treatment accurately.

There are several "red flags" that parents should be aware of when trying to decide which treatment to choose for their child. Unfortunately, there is no magic cure for autism. When considering a treatment, parents should watch out for exaggerated claims of a cure, especially if the treatment requires a significant financial commitment. In addition, parents need to be aware of the marketing aspect of what they read. No one will advertise a treatment with testimonials saying that a treatment does not work, but positive testimonials do not always mean that treatments are effective. Additionally, when pursuing biomedical treatments, parents should always consult with a pediatrician or some other medical professional. Finally, they should be cautious of treatments that may cause direct physical harm to their child.

Susan M. Wilczynski, PhD, BCBA, is Executive Director of the National Autism Center and chair of the National Standards Project. A licensed psychologist and Board Certified Behavior Analyst, Dr. Wilczynski has authored numerous articles on the treatment of autism spectrum disorders.

Leslie Sutro, PhD, is a licensed psychologist at the National Autism Center. Dr. Sutro has significant experience providing consultation services to schools and families seeking appropriate and effective services for children with autism spectrum disorders.

successful outcome of ABA in the development of this particular skill, they arranged for Cameron to receive regular ABA therapy.

Seek Evidence of Effectiveness

It is not uncommon for families to take an eclectic approach as they search for the best treatments for their children. Although this may seem like a way to

take advantage of the best aspects of every therapy, this approach often assumes that all treatments for autism are equal. Unfortunately, they are not. Some have evidence showing their effectiveness and others do not.

Fortunately for the Carter family, their approach led them to ABA, which has far more research support than any other treatment or therapy for children

with autism. ABA therapists use positive reinforcement, teaching in small steps, prompting, and repeated practice to facilitate language development, improve behavior, develop social skills, and support independent living.

For Cameron's May Institute ABA therapist, Jocelyn Priester, MS, BCBA, the Carters' multi-therapy approach presented some challenges. "We noticed an

increase in problem behavior when Cameron was going through chelation,” says Jocelyn. “The doctor had told his mom to expect that. Because it’s an internal event (the chelation) that I couldn’t control, I would just do the best behavior management I could. We had behavioral goals in place, so I worked on those.”

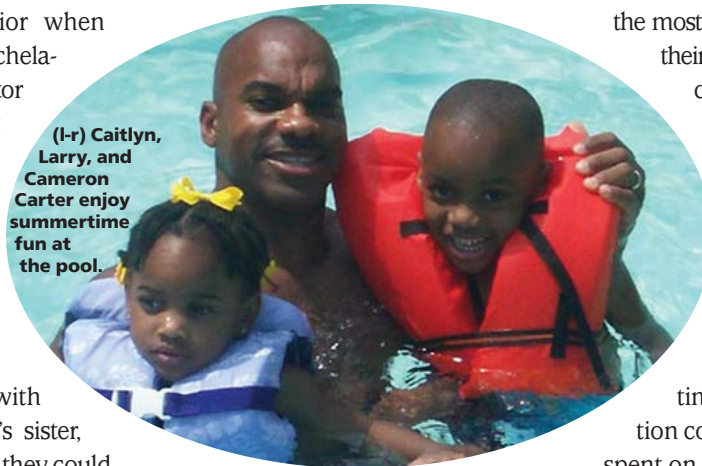
Jocelyn also worked with Christal, Larry, and Cameron’s sister, Caitlyn, recommending things they could do at home to support his ABA therapy, including how to encourage full speech. The family is very pleased with the results.

“With ABA, we saw a huge increase with language,” says Christal. “Cameron had words...but he wasn’t using full sentences. His therapists required him to speak in sentences and showed us how to do it, too! Before ABA therapy, if he wanted juice, he would just say ‘juice.’ With the help of ABA, he learned how to say, ‘I want juice, please.’”

“ABA also stimulates more spontaneous speech,” Christal continues. “He’s gone from not even saying ‘Mommy’ to being able to name the people in the photos I show him. Now he can tell you my cell phone number and where his grandmother lives. He’s identifying letters and colors and animals. This is huge. For someone who is not living with autism, it may not seem huge, but for us, it is amazing what he has been able to accomplish.”

Christal has become such a strong advocate of ABA that she established a community play group and pursued funding to bring together children with autism and their typical peers. The group teaches positive social skills and provides an opportunity for parents to support one another. Christal hopes to establish scholarships to assist parents seeking ABA services.

Cameron continues with ABA therapy, along with the GFCF diet, and supplements such as cod liver oil and vitamin B12 injections, although Christal says there are other treatments she might consider. “We continue to look at what’s out



(l-r) Caitlyn, Larry, and Cameron Carter enjoy summertime fun at the pool.

there and make decisions about treatments,” she says. “We discuss everything and make sure we are in agreement before we start any type of treatment.”

It is understandable that parents are drawn to eclectic programs because of the possibility that one of the treatments will hold the key to success for their child. When they are making decisions about their children’s treatment, however, it is critical that they look for therapies that have

the most research support in order to use their precious time, energy, and financial resources wisely.

It is also important to recognize that combining treatments could dilute or compromise the effectiveness of a particular intervention—because the treatments might interfere with one another, or because the time required for one intervention could impact the amount of time spent on another intervention.

For a child with autism, time is of the essence. Decisions made about treatment can make a significant impact on that child’s long-term success. This is particularly true in the areas of language and social behavior. Early diagnosis followed by effective treatment can literally mean the difference between a child: (a) ultimately mastering language, having typical social interactions with family and peers, and fully integrating into mainstreamed public school environments, or (b) not learning to speak, remaining socially isolated, and needing intensive educational, behavioral, and rehabilitation services throughout life.

Clearly, we have not yet solved the puzzle of autism. We must continue to work incredibly hard with each and every child in an individual manner specific to that child’s unique needs, learning style, and family situation. We give children with autism the best possible chance if we use the procedures that have the greatest documentation of effectiveness. •

Alan Harchik, PhD, BCBA, is May Institute’s Chief Operating Officer, a licensed psychologist and teacher of children with disabilities, a 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. For the past three years, Dr. Harchik has written monthly, autism-focused columns for newspapers in Massachusetts. He serves as an expert consultant for the Civil Rights Division of the United States Department of Justice.

Patricia Ladew is a senior writer for May Institute’s Office of Communications. She has specialized in healthcare writing for the past 20 years.

Resources

Suggested links to information about autism, treatment, and resources:

Autism Society of America

www.autism-society.org

Centers for Disease Control and Prevention

www.cdc.gov

May Institute

www.mayinstitute.org

Military OneSource

www.militaryonesource.com

MyArmyLifeToo

www.myarmylifetoo.com

National Alliance for Autism Research (Has merged with Autism Speaks)

www.naar.org/naar.asp or

www.autismspeaks.org/index.php

National Autism Center

www.nationalautismcenter.org

National Institutes of Health

www.nih.gov

Organization for Autism Research

www.researchautism.org

TRICARE

www.tricare.mil