

Setting the Standard for Autism Treatments

National Autism Center Releases Groundbreaking Report

By Susan M. Wilczynski, Ph.D., BCBA and Eileen G. Pollack, M.A.

In the United States and throughout the world, our understanding of autism and other related disorders continues to evolve. Parents, educators, and health professionals today benefit from significant advancements in both the diagnosis and treatment of autism. Five decades of research have increased our knowledge of these complex developmental disabilities and led to a broad range of treatments.

The need to evaluate and select from this long list of treatment options can be daunting, however. The good news is that information is available to help us focus on the treatments or interventions that have evidence of effectiveness.

Diagnosis is the Beginning

It is a scenario that plays out in countless homes across the country each year. A very young child begins showing signs of possible developmental delays. Or a child who has been meeting typical milestones seems to stop learning new skills, or begins to lose skills. Over time, parents realize that something is “not quite right.”

A family that sets out to discover the root cause of these symptoms may encounter a number of obstacles along the way, including conflicting opinions, long waiting lists for assessments, a lack of qualified practitioners, and possible misdiagnosis. For some of these families, the eventual diagnosis will be autism or a related Autism Spectrum Disorder (ASD). The impact of the diagnosis is overwhelming to most and often reverberates throughout the lifetime. An ASD diagnosis will require significant time, energy, commitment, and resources. For many parents, it will be the first step in gathering the critical information they will need to help their children grow and develop.

Selecting Effective Treatments

“We absolutely did not know where to begin,” says Rebecca Woodcock, a special needs teacher from Massachusetts whose son Gavin was diagnosed with autism last summer when he was two-and-a-half years old. The only recommendation from the doctor at the hospital was to call an agency that provided applied behavior analysis, or ABA. The doctor did not explain ABA or what

it entailed.

“We joined our local support group, where they talked about all sorts of unconventional, bio-medical treatments,” Rebecca continues. “I wanted to try hyperbaric oxygen therapy. My husband Matt is a scientist and approached our search for treatment from a research-based point of view. We agreed that if the clinic could provide research that showed the treatment worked, we would spend the money (thousands) on the therapy.” She and Matt asked for documentation, but never received it. “That’s when I realized that there may be lots of ‘treatments’ out there making claims they can’t support. That was very disappointing, because they seemed like ‘quicker fixes.’”

“I did Internet searches and listened to advice from everyone,” says Rebecca. “It is a horrible feeling to not know how to help your child.”

The sheer volume of information available presents a formidable challenge. Along with the dramatic increase in diagnosed cases in recent years – the newest estimates place the incidence rate as low as one in 100 children – there has been an explosion in the number of potential treatments.

A simple search on the Internet for “autism treatment” yields an astounding 1,740,000 results. “Autism intervention” is even more daunting, producing more than three million results. Parents like Rebecca and Matt are often inundated with conflicting and confusing information about treatments. It is almost impossible to know where to begin.

The National Standards Project

In 2005, the National Autism Center launched a project that it hoped would answer one of the most pressing public health questions of

our time — how do we effectively treat individuals with ASD? If done well, the results would help guide families like Rebecca and Matt in their quest to find the best treatment for their son by providing information about which treatments have been shown to work.

The Center invited dozens of the country’s top autism experts to join the effort. These experts, leaders in the fields of psychology, speech-language pathology, medicine, behavior analysis, and positive behavior supports, would spend the next several years contributing to the National Standards Project. The project began with an initial review of more than 7,000 research abstracts. An international group of scientists then evaluated the 775 studies that make up the autism treatment literature – the largest number of studies ever reviewed.

Not all of these studies were equally able to answer the question “Is the treatment effective for individuals on the autism spectrum?” Some studies were very well designed, making it easy to know if the treatment was effective. Some studies were not as well designed, and even scientists would not be able to determine if the treatment was effective. The experts of the National Standards Project applied a set of scientific criteria to each of the studies. By applying the same criteria to all studies, the experts were able to clearly identify which treatments were effective.

The Results of the Project

The National Autism Center announced its results in September of 2009 in the National Standards Report. It is the most comprehensive analysis available to date about treatments for children and adolescents (under the age of 22) with ASD.

In the end, the project identified 11 “estab-

Established Treatments from the National Standards Project

The findings of the National Standards Project include the identification of 11 Established Treatments. These are defined as treatments that produce beneficial outcomes and are known to be effective for individuals on the autism spectrum.

The 11 Established Treatments are:

- Antecedent Package
- Behavioral Package
- Comprehensive Behavioral Treatment for Young Children
- Joint Attention Intervention
- Modeling
- Naturalistic Teaching Strategies
- Peer Training Package
- Pivotal Response Treatment
- Schedules
- Self-management
- Story-based Intervention Package

For definitions about each of these treatments, and more information about all the treatments reviewed, or to download a copy of the National Standards Report, please visit www.nationalautismcenter.org.

lished” treatments (see sidebar for more detailed information). These are treatments that have been thoroughly researched and have sufficient evidence to show they are effective for individuals with ASD. They target the core symptoms of autism (such as difficulties with verbal and nonverbal communication, problems with social behaviors, sensory sensitivity, anxiety, etc.), along with many of the other challenges related to autism.

In addition to the 11 Established Treatments, the report identified 22 “emerging” treatments that have some evidence of effectiveness, but still require more research. A small percentage of treatments fell into a third category called “unestablished” treatments. The five unestablished treatments have inadequate or no evidence of effectiveness. While some have been investigated through research, the studies were not designed in a way that produced clear results.

Research as Part of a Comprehensive Approach

If they understand the level of evidence that supports a broad range of autism treatments, parents can make better decisions about treatment for their children. Because of the level of detail in the report, families for the first time can find specific information about the age groups, treatment targets (such as increased skills and decreased behaviors), and diagnostic populations (autism, Asperger’s, and PDD-NOS) to which these treatments have been applied.

Although research findings are one critical ingredient of a comprehensive approach called evidence-based practice, they are not the only factor that should influence treatment decisions. Evidence-based practice integrates research findings with other important factors that recognize the individual needs and circumstances of the child or adult receiving the treatment. These other factors include the judgment and data-based clinical recommendations of qualified professionals, the values and preferences of the individuals with ASD and those who care for him/her, and the capacity of the professionals to deliver the treatment correctly.

Rebecca and Matt are already using the information from the report to guide their decisions about treatment for Gavin. They are cautiously optimistic that their school district,

and others, will take advantage of the information in the National Standards Report to fill gaps in knowledge and capacity. “The lack of accurate information is astounding,” says Rebecca. “I hope school districts embrace this report and use the information to give teachers the tools they need to provide effective instruction to students with autism.”

Awareness, Information, and Hope

There is no question that the journey for Rebecca and her family will be complex, challenging, and at times isolating.

“My son was diagnosed with autism 15 months ago and I still have days that are hard to get through,” she shares. “I know there is hope, but that diagnosis has left me feeling like a lone crusader. I hope that changes. I hope that in the future, when other people receive that diagnosis, they don’t feel so isolated. Maybe, with more awareness, information, and sensitivity that can change.”

It is the fervent hope of the National Autism Center, and the dozens of individuals and organizations that have participated in the development of the National Standards Project, that the results of this project will help to affect that change.

About the National Autism Center

The National Autism Center is dedicated to serving children and adolescents with Autism

Spectrum Disorders by providing reliable information, promoting best practices, and offering comprehensive resources for families, practitioners, and communities. •

Susan M. Wilczynski, Ph.D., BCBA, is the Executive Director of the National Autism Center and Chair of the National Standards Project. Dr. Wilczynski also spearheads “Pathways,” a parent education series for parents whose children have recently received a diagnosis on the autism spectrum. Dr. Wilczynski has authored multiple articles and book chapters on the treatment of Autism Spectrum Disorders and has co-edited the book *Effective Practices for Children with Autism*. A licensed psychologist and a board certified behavior analyst, Dr. Wilczynski has held academic appointments at the University of Southern Mississippi, the University of Nebraska Medical Center, and UMASS-Boston. Dr. Wilczynski frequently presents at national and international conferences.

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