Parent to Parent
Making the Case for Evidence-based Practice

Parents who have children with a new ASD diagnosis are faced with more information than they can possibly absorb, and a series of decisions to make as their children grow and develop. They must understand the world of ASD well enough to navigate it.

By Hanna C. Rue, Ph.D., BCBA-D, and Patricia Ladew National Autism Center

For families of children with autism spectrum disorders (ASD), finding information about treatments is easy. What’s difficult is finding reliable information that has withstood the rigor of science, is comprehensive in scope, and is accessible and easy to read.

Recently, several parents who have children on the autism spectrum joined forces with professionals associated with the National Autism Center to author a manual that is an informative, easy-to-understand resource for families in search of the best treatments for their children with ASD. This article provides the perspective of two parents who participated in the development of the guide.

For Janet Amorello, whose 16-year-old son Sam was diagnosed with autism more than a decade ago, collaborating with the National Autism Center to create this manual was a rewarding experience, and an opportunity to help parents who face the same kinds of challenges that she and her family faced years ago.

“When my son was younger, there were a lot of books about what to do, but there wasn’t anything that told me what had been researched,” says Janet. “There wasn’t a book that really explained the scope of what was out there in terms of treatments. Those were scary days – everyone seemed to be selling a ‘cure.’ Parents often have limited financial resources, but we are all susceptible to buying hope. Of course I wanted to do what was going to work. But I just didn’t know what that was.”

Parent author Katherine Bray, mother of 12-year-old Christian who has autism, cerebral palsy, and epilepsy, advises parents to conduct their own research and find sources that are reputable. “Using this guide as a resource will cut down on the amount of research parents need to do,” she says. “It gives them the tools they need to implement programs for their children that will impact their future success.”

A guide to decision making

The 200-page manual—“A Parent’s Guide to Evidence-Based Practice and Autism”—is available from the Center’s site as a free download. Its aim is to help parents as they make decisions about how to best help children with ASD reach their full potential. The first chapter includes a review of autism spectrum symptoms (including difficulties with verbal and nonverbal communication, problems with social behaviors, sensory sensitivity, etc.), and conditions that may be co-occurring (such as depression, attention deficit hyperactivity disorder, and obsessive-compulsive disorder).

The second chapter, entitled “Research Findings,” describes effective treatments that were identified through the National Autism Center’s multi-year National Standards Project [SEE RELATED SIDEBAR]. The findings included 11 “established treatments” that produce beneficial outcomes for individuals on the autism spectrum.

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Other chapters discuss the importance of professional judgment and data collection, the role of family preferences and values in the decision-making process, and factors parents should consider when choosing a team of professionals. The guide provides a checklist parents can use when they are trying to find experienced individuals and/or organizations that will be the best fit for their child’s treatment team. It also includes the full text of the Findings and Conclusions report from the National Standards Project.

Translating research into practice

As parents of child with ASD know, identifying the best possible treatment or treatments for children on the autism spectrum is an overwhelming task. In fact, it took the National Autism Center’s “expert panel”—comprised of leaders in the fields of psychology, speech-language pathology, medicine, behavior analysis, and positive behavior supports—several years to review thousands of research abstracts and evaluate hundreds of studies before they were able to determine which treatments had sufficient evidence to support their effectiveness, and which did not.

Translating that information into a format that could be easily read and understood by families and other “lay people,” posed another challenge— one that parent authors were well equipped to handle. Throughout the manual, “Parent-to-Parent” sections suggest strategies, share lessons learned, and offer words of encouragement and support. In the guide’s Introduction, the first “Parent-to-

Data Collection

The idea of collecting data may seem overwhelming. But it becomes easier over time, and there are ways to build it into your family’s daily activities. Like every aspect of your child’s treatment plan, knowing how to record data is very important. Not all professionals/practitioners have received sufficient training on data collection. This means that you may need to explain to other professionals on the treatment team how to correctly record data or ask them to receive training elsewhere. That way, everyone can see which treatments have helped your child build important skills or decrease problem behaviors. Data also tell you whether or not these improvements are sustained over time and if your child can demonstrate a skill in new situations and/or with different people—which is critical for people on the autism spectrum.
The National Standards Project

How do parents decide what treatments are the most effective for their child and acceptable to the family? The National Autism Center set out to answer that question when it launched an initiative called the National Standards Project (NSP).

That first phase of the NSP was the largest systematic review ever conducted of the treatment literature for individuals with an ASD. Its purpose was to identify high-quality scientific studies that evaluated treatments for individuals with an ASD. As part of this project, a team of national experts reviewed 775 treatment studies published between 1957 and 2007, and rated them on the quality of science used and the effectiveness of the treatments presented. The 775 studies included educational and behavioral treatments for individuals under the age of 22 with a formal diagnosis of autism, Asperger’s disorder, and pervasive developmental disorder not otherwise specified (PDD-NOS).

In 2009, the National Autism Center released the results of the first phase of the NSP, which identified 11 treatments as established, 22 treatments as emerging, and five treatments as unestablished.* Established treatments were identified as such because there was sufficient scientific evidence to confidently state that each of the identified treatments produced a beneficial effect for children with an ASD. Some examples of interventions identified as established include providing choices, behavioral sleep packages, Social Stories™, video modeling, and visual or written schedules. The complete list of the 11 established treatments follows:

- 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 Packages

Parent” box gives the following advice:

When you have a child with ASD, you get exposed to technical jargon that professionals use. Sometimes it can feel overwhelming and you think, “Do I have to go back to school and get a degree in this? It’s an unfortunate reality that professionals use a lot of jargon.

The authors of the chapters in this manual are no exception. They all tried to explain what they mean whenever they use technical jargon. Even so, there may still be times when you feel overwhelmed as you come across several technical terms in a row. Please don’t let this stop you from using this manual! If you feel stressed, put the manual aside for a little while, but come back to it. You don’t have to know all of these terms. The most important goal is for you to understand these concepts well enough to advocate on your child’s behalf so she gets access to the services that will help him or her grow as a person.

The parent perspective

When Janet was asked to contribute to the guide, she agreed right away. “I had a very personal investment in this project,” she explains. “I’ve lived it. Ask any parent of a child with autism and they will tell you—we’ve been there, done that!”

Janet contributed to the chapter that discusses family preferences and values. This chapter positions parents as the experts when it comes to their children, and stresses the importance of cultural variables, religious beliefs, and family structure when it comes to selecting treatments. It also encourages parents to feel comfortable about becoming strong advocates for their children.

This is a message that resonated with Janet, who urges parents to take an active role in their child’s treatment and share their perspectives with their child’s treatment team. She once told a clinician, “I don’t doubt for a moment that you care about my child. But long after you’re gone, I’ll be here. You might wake up some day and wonder ‘What ever happened to that funny kid with the big hair,’ but I will be dealing with who he becomes. I will be the constant in his life and you will not.”

Katherine contributed a chapter about professional judgment and data collection. “I thought these were really important topics because parents are charged with leading the team for their child’s education and social development. Understanding how to collect data, measure success, and develop realistic expectations for your child helps you to make recommendations to the school district about what should be included in your child’s IEP (Individual Education Program). And when you have the data to support your requests, you are more likely to meet with success.”

Katherine has been collecting data for
Christian’s treatment program for a number of years. Most recently, she and Christian’s teachers and therapists have been focusing on daily living skills. Working together, they implemented a data collection process to use as they help him learn to dress himself. “We’re teaching him the steps and recording his progress every day,” says Katherine, who has a chart at home where she records how many prompts Christian needs to put on his pants. Christian’s teachers and therapists work with the same chart. “You need to be collecting the same information, in the same way,” Katherine explains. “so there is consistency between settings.”

While Christian is not yet dressing independently, he is making steady progress. Most recently, he has learned to make sure the tags are in the back when he puts on his boxers or his pants. “That’s a big thing,” says Katherine. “Small steps to independence, is what I say.”

In one of her Parent-to-Parent sections, Katherine acknowledges that collecting data can seem daunting [SEE RELATED SIDEBAR]. “But you can make it easy and fit it into your life,” she states. “Data collection can be a series of tally marks, or it can be recording the fact that your child’s last tantrum lasted only three minutes rather than 10 minutes.” She also recommends using technology —special applications on smart phones and touch tablets—to make the process of recording information easier.

The clinical perspective
Although tools and resources like this manual can make a significant difference in the lives of families affected by autism, we recognize that there are no easy solutions or prescriptions.

Parents who have children with a new ASD diagnosis are faced with more information than they can possibly absorb, and a series of decisions to make as their children grow and develop. They must understand the world of ASD well enough to navigate it. They must learn enough about treatment options to make good choices. Once decisions are made (and revisited), they need to learn about how to use data to determine if the treatments are actually working.

Families are also tasked with finding the best possible professionals to deliver the treatment; not an easy task given waitlists, funding obstacles, and a lack of experienced providers in many parts of the country.

What works best for one child may not be as effective for another. Even a treatment that works well for a child may not be the best choice, depending on factors—such as finances, work schedules, cultural norms, support of family and friends—that might impact the ability to deliver that treatment in an optimal way.

Finally, parents understand better than anyone how an ASD diagnosis, and the impact of all the challenges listed here, can have a profound effect on their family. Siblings and other family members’ lives are impacted as decisions and adjustments are made. Plans for the future take on a different weight.

“A Parent’s Guide to Evidence-Based Practice and Autism” seeks to address some of those issues to better prepare families for the challenges they face.

“My hope for the manual is that it becomes the ‘gold standard’ for parents,” says Katherine. “They can access it online for free and review things that may be of concern for them at any given time.”

Janet is pleased with the final product. “There’s a lot of good information in this guide,” she says. “It takes you through, step by step. It does it in a way that’s not scary and uses words that parents can understand. It isn’t so clinical that it’s difficult to dissect. I hope it gets in the hands of a lot of parents who are just starting out. I hope it’s helpful to families. You always want things to improve, not just for yourself, but for everyone.”

The work continues
The National Autism Center is currently working on the NSPII which is a follow-up to the original project. The focus of the NSPII is to review the treatment literature for adults (i.e., 22 years of age and older) with an ASD, as well as for individuals identified as “at risk” for developing an ASD. Additionally, the NSPII will update the findings for individuals under the age of 22. Once again, experts from across the country are participating in the project. To date, there are over 400 treatment articles that will be evaluated for quality of science and the effects of treatment. The results of the NSPII will be published later this year.

*The NSPI’s Findings and Conclusions report includes additional information about established, emerging, and unestablished treatments. This report, the Parent’s Guide, and an Educator’s Guide are all available as free downloads from the National Autism Center’s website at www.nationalautismcenter.org.

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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.