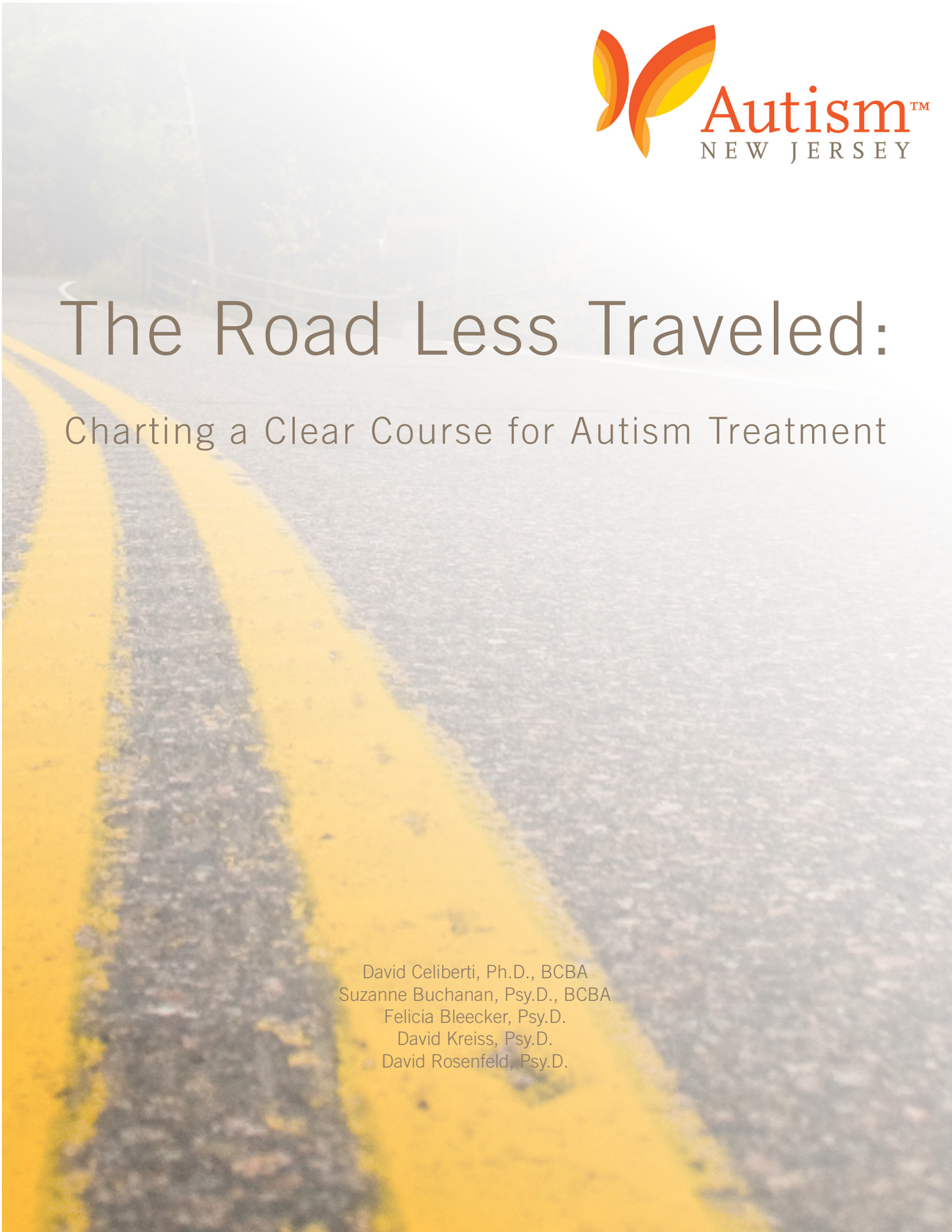

Autism™ NEW JERSEY

The Road Less Traveled:

Charting a Clear Course for Autism Treatment

David Celiberti, Ph.D., BCBA
Suzanne Buchanan, Psy.D., BCBA
Felicia Bleecker, Psy.D.
David Kreiss, Psy.D.
David Rosenfeld, Psy.D.

The current landscape of treatment options for parents of children with autism can be a confusing and unsettling one. To help explore this challenge, let us offer the following scenario:

> *Your child has been diagnosed with cancer. While searching for medical treatment for your child, you come across a variety of medical providers. Some practice 1980s style medicine and others practice state-of-the-art medical techniques. The first group appears unaware of the latest scientific advances in treatment, whereas the second group is embracing and making the most of recent scientific advances within the field of pediatric cancer care. Given the tremendous stakes at hand and your concern for the health and well-being of your child, virtually all of you would choose those doctors who provide the most current, scientifically- validated medical approach to treat your child's cancer.*
>
> *Fortunately, the "treatment of choice" for cancer is fairly well-defined. In pediatric cancer care, there is a shared commitment to using science to guide treatment. Although experimental drug trials are a slow process, once drugs and drug protocols are approved, the treatment of choice is clear. Furthermore, there are a variety of negative consequences for those physicians who ignore and fail to integrate science-based advances in their treatment of cancer (e.g., sanctions from licensing boards, malpractice lawsuits). Although there is certainly a range of expertise among cancer specialists, well-established medical training programs and licensing criteria help ensure a high-level of competence from all. Parents of children diagnosed with cancer do not need to exert painstaking efforts to acquire information about cancer treatment and locate appropriate medical providers, and children diagnosed with cancer are typically able to avoid waiting lists and access timely treatment. Finally, the professional community and society at large do not fault parents for pursuing the most current, scientifically validated intervention for their child's cancer.*

Now let's turn to the experiences of parents of children diagnosed with autism and related disorders. In contrast to the above scenario, parents of children with autism will certainly encounter providers with a range of commitment to the latest scientific advances. Unfortunately, there are many providers who are unaware of scientifically-validated technology, as well as others who are aware but choose to reject this technology outright. It is our view that scientific evidence represents the best source of information to guide treatment selection. Parents of children with autism often have to sift through much literature to locate information about scientifically-validated intervention. With the increasing demand for services, parents often encounter a shortage of providers and extensive waiting lists for treatment. This often occurs when their child is at an age when timely intervention is of the essence. Even among the pool of providers who claim to embrace scientifically-validated treatment for autism, there exist tremendous differences in quality and expertise. Currently, the gap between what is known about effective autism treatment and what is practiced is quite wide. Sadly, that is the reality of autism treatment.

It is our view that embracing a scientific method is the foundation of providing state-of-the-art treatment for autism and a reliable source of hope. Those of you who question this notion should consider the scenario above again. By respecting the scientific method, physicians who provide cancer care can differentiate between effective and ineffective treatments and make choices carefully and responsibly. In cancer treatment this process has been conducted through careful analysis of the types of cancer, the types of treatment, and the variable outcomes for children. This process includes the following: knowledge of current best practice; hypotheses to improve the course of treatment and the children's prognoses; direct observation and data collection to test the hypotheses; and finally, the publication of the results, their implications for the field, and their directions for future research. This scientific process has also advanced the treatment of autism.[1]

Although research has suggested a biological basis for autism,[2] there are currently no scientifically- validated medical treatments to address the core deficits of autism. Unfortunately, many parents of newly diagnosed children believe that medical treatments do exist that may eliminate most, if not all, of the symptoms or manifestations of autism, perhaps even proving to be a cure. This expectation may be due in part to the fact that the medical model for many other disorders is well established. As an example, the treatment for strep throat may involve a very specific class of antibiotics administered three times per day for 10 days. Although the cause of this infection is rather clear, autism, by contrast, is widely believed to have multiple causes that vary across individuals. Nonetheless, drug interventions for individuals with autism have been widely attempted targeting a vast array of symptoms associated with autism.

These trials have included such medications as antihypertensives, anxiolytics, anticonvulsants, antipsychotics, antidepressants, antihistamines, and stimulants.[3]

In their search for science-based treatment for autism, parents will certainly encounter Applied Behavior Analysis (ABA). The field of ABA has evolved considerably over the last few decades.[4] Technologies to address learning difficulties and to target challenging behaviors have become increasingly effective, refined, and precise. It cannot be overstated that the data- based literature supporting interventions for individuals with autism based on the principles of ABA is indeed abundant. Every year the technology is expanded and enhanced through research that is carefully documented, scrutinized by professional reviewers and ultimately published in scientific journals.[5] As a result of this ever-increasing body of scientific support, a number of state and federal agencies have looked at the wide array of available treatment for autism and have determined that ABA is the only treatment approach that is scientifically validated.[6] It is disheartening that so many providers in the field ignore these recommendations of these agencies. (On a practical note, you will find that information about ABA is also available in books that provide an overview of the ABA model and teaching strategies derived from ABA.[7])

It is important to note the treatment of autism using ABA does not produce overnight results, nor is ABA a cure for autism. Rather, ABA requires a strong and intensive commitment with respect to time, structure, and consistency.[8] Despite this commitment, "recovery" may be a viable outcome for only some individuals with autism. Furthermore, high-quality ABA services are not widely available and are often difficult to access. The shortage of qualified and competent ABA providers has created a breeding ground for less qualified individuals to fill the gap between supply and demand. In other words, not all behavior analysts are "created equal," and there is great variability in the training and supervision of these professionals.[9] Consequently, not all ABA programs are consistent with best practice and the commitment to ongoing assessment of progress can vary widely. Yes, individuals with autism are likely to benefit from comprehensive and state-of-the-art ABA programs because many of the techniques used within an ABA program have strong scientific support. Yet, how "comprehensive and state-of-the-art" a program is often depends on the qualifications of the behavior analyst and the teaching staff. Parents should not believe that once their child with autism is participating in an ABA program, the questions about treatment are answered. While one major question regarding the type of educational program has been answered, there are countless other questions to ask in order to effectively monitor the quality of the treatment provided (e.g., what is being targeted, how is it being targeted, are the desired outcomes being achieved?). Thus, parents should always be active participants in the decision- making process within an ABA program for their child.

As stated above, ABA is not an intervention with a track record of "overnight" success. Unfortunately, there are no quick and easy treatments for autism that have been proven to be successful through research. As a result, both parental and professional interest in alternative treatment approaches has remained strong partly due to their often promised success and ease through which they are carried out. The term "magic bullet" is often associated with a straightforward and precise intervention for a specific condition. The search for the "magic bullet" to treat autism is elusive, as it has been with other disorders.

> *In the 1970s, Ritalin was touted to be the miraculous "magic bullet" for Attention Deficit Hyperactivity Disorder (ADHD). To date, however, the published research supporting the efficacy of this medication has suggested some positive changes, but there has not been an abundance of data documenting long-term elimination of the symptoms associated with ADHD. The last few decades have revealed that Ritalin is not a "magic bullet." While it helps many children with ADHD attend, it should not be assumed that children will then automatically know when, where, and to which aspects of the environment they should attend. Nor will medication result in the appearance of missing academic content areas and prerequisite skills. Furthermore, it is not realistic to expect dramatic changes in the social arena. Peers may not automatically embrace a child with ADHD who a week prior was significantly disruptive to the class and unable to wait his or her turn on the playground. Psychostimulants such as Ritalin may be part of the treatment for an individual with ADHD, but not the solution in and of itself.*

This example suggests that even effective pharmaceutical interventions for autism may not be sufficient in and of themselves. Progress may be maximized only when combined with a comprehensive approach to teaching new behaviors (such as behavioral intervention drawn from ABA) to address the development of important skills that do not automatically appear through the use of medication.

For one parent, the example above may reaffirm his/ her commitment to science-based treatment approaches. Another parent may take a different perspective – believing that some of the various treatment options could be helpful in treating autism. So, let us now take a look at what other treatments exist - as there are currently dozens of other intervention options. These approaches include, but are not limited to, extensive dietary modifications, medications, vitamin therapy, hormone therapy, facilitated communication, gentle teaching, biofeedback, electromagnetic therapy, infusion or injection of immunological substances, sensory manipulations such as auditory integration, massage of the scalp, specialized prism lenses, complex rhythmic drumming patterns, exposure to fluorescent lights, the Miller Method, significant manipulations in parent-child interactions such as holding therapy and Option therapy, as well as treatments involving therapeutic contact with animals such as dolphins and horses.

There is no reason to doubt that the number of intervention options will only increase with time. In fact, every year new interventions to treat autism are proposed. The internet is filled with ongoing dialogue and volumes of anecdotal information advocating the use of these alternative treatments. Interventions such as secretin and facilitated communication have received substantial and widespread media coverage prior to the emergence of adequate scientific evidence supporting their use. Testimonials boasting vast improvement or even a cure for autism can be extremely enticing to parents or caregivers, raising their hopes and expectations. Unfortunately, with the exception of some medications, it has been noted repeatedly that the advocates of these treatments to date have not generated adequate scientific support for such interventions.[10]

It is our opinion that the responsibility to demonstrate efficacy lies with the providers of that particular intervention. This position has been shared by others.[11] Unfortunately, many have abandoned this important responsibility and have instead asked consumers to rely only on anecdotal reports, descriptive published reports, or poorly designed research. It is important to alert our readers that there have actually been published articles and policy statements discrediting the use of many interventions including facilitated communication,[12] auditory integration training,[13] and sensory integration training.[14]

Nonetheless, the abundance of possible treatments for autism continue to be a source of temptation for some parents and professionals trying to maximize the overall functioning and quality of life for their child or client. The enormous list of possible approaches is partially because numerous disciplines are involved in autism treatment. For some parents, the availability of such a wide range of alternative treatment approaches can be reassuring. For others, an increasing number of options can lead to false hopes that may result in disappointment, frustration, and burnout. Parents may come to regret not considering or trying a treatment approach that others have claimed to be beneficial. Parents may also find themselves second guessing their decisions or feeling unsure about whether they are doing what is best for their child. In the absence of scientific support for alternative treatment approaches, parents of individuals with autism often have to rely on their own investigation of various treatment options in order to determine which would be the best course of action for their child. We feel that this is a very unfortunate and even unsettling role for parents to assume.

It is understandable that parents have various reactions and perspectives regarding how to make treatment decisions. For example, many parents are not tempted by the vast number of treatment options that are available. These parents are naturally skeptical of those treatments that do not have scientific support. They may cautiously view alternative treatments as experimental and not as a viable option. Other parents may have explored one or more alternative treatments and found themselves unimpressed or even disappointed with the outcome. Yet, still other parents have worked with and become influenced by applied behavior analysts who are rather forthright in their criticisms and dismissal of alternative interventions. The persuasive arguments by these professionals have discouraged some parents from pursuing treatment approaches that lack scientific support.

Unfortunately, such strong positions have alienated other parents and have led many to pursue these alternative interventions secretly and with little to no professional guidance. Such concealed efforts run counter to the concept of parent-professional communication that is essential to any effective ABA program. A valid and objective evaluation of a child's skill acquisition and behaviors is also negatively impacted when parents and caregivers do not feel comfortable reporting their child's involvement and participation in alternative treatments. As a result, teaching staff may be at a loss to understand a sudden change in classroom behavior that may indeed be an adverse reaction to another treatment (e.g., a dietary intervention). These professionals may lose sight of the notion that parents and caregivers are driven to help their children get better. While they want to make informed decisions regarding alternative treatments

for their child, parents understandably may be willing to try any techniques which offer the hope of improving their child's outcome.

At the other extreme, there are professionals who misrepresent, minimize, or outright dismiss scientifically supported treatments and the scientific method. We have observed that not all professionals in the field rely on scientifically-validated information when endorsing and/or providing interventions. One rationalization for this flexible approach is based on the belief that no one approach, including ABA, works for all individuals. Yet, a "try everything" mindset may lead a parent to believe that the treatment of autism should be based upon the quantity of interventions, as opposed to quality of the interventions. As a result, parents may spread their available resources too thinly in their efforts to create a multi-layered treatment program for their child. In addition, unforeseen negative interactions may occur from the combination of two or more interventions that should not be implemented at the same time.

There is a possible silver lining here: perhaps the provision of multiple services may benefit the child. This situation calls for even greater attention to treatment evaluation and an assessment of the unique contribution of each method. A similar evaluation process may also be necessary when one method relies on an array of components as many treatments for autism do. It is in the child's and the family's best interest to evaluate these services to ensure that each one is a worthwhile endeavor. Doing so will enable parents to make the most of their time and resources. When faced with such complicated questions, many parents take a best-odds approach. The child participates primarily in an ABA program and the parents cautiously introduce and evaluate treatments that have not yet been scientifically validated. Again, having to make such important decisions with little support, resources, and information is a difficult task, however, it is hoped that the considerations detailed in this document may alleviate some of this burden.

We believe it is important to provide parents and caregivers of children with autism with a step-by-step approach to the investigation of treatment options, thereby enhancing their chances of making the most informed and effective decisions for their child. It is our view that the scientific practices and high standards used within of Applied Behavior Analysis offer all of us very useful tools for negotiating the variety of treatment approaches available in the field.

We recognize that our readers possess varying familiarity with ABA. Many may not be aware that the assessment and evaluation methods utilized within ABA can actually provide parents with a useful way of exploring various treatment choices for their children. We can identify and clearly define the behaviors that we wish to target for change.

- Once a definition of a target behavior is created, we can track the frequency, intensity, and/or duration of the target behavior's occurrence before the treatment is ever implemented (baseline data). If it is not known how frequently the target behavior occurred before treatment, it will be impossible for us to assess the effectiveness of the treatment in increasing or decreasing the behavior.
- Next, we can collect data on an ongoing basis as the treatment is implemented to observe trends in the target behavior. Are behaviors increasing, decreasing, or remaining unchanged?
- After the treatment has been implemented for a sufficient amount of time, we can make a determination regarding the effectiveness of the treatment. At this point, it may be necessary to maintain, alter, or discontinue treatment.

These evaluation procedures above are integral components of interventions based on ABA and are routinely carried out within well-run ABA treatment programs. However, all interventions should be subjected to the same scrutiny when it relates to something as precious as the safety, well-being, and potential of an individual with autism. The responsibility to objectively assess progress should not diminish with the implementation of alternative treatment options. In fact, interventions that lack a sound body of scientific support should actually be evaluated even more rigorously.

We have included a series of questions for consideration when evaluating treatment approaches for autism. It is followed by a summary of the key questions that can readily be used when interviewing prospective service providers including those who offer ABA and those who do not (see Appendix A). As can be seen in Figure 1, information gathering and decision making can be a sequential process:

- Phase I explores whether the intervention in question is a viable, safe, and pot
- entially worthwhile intervention. Published scientific evidence will likely address many of the questions included

in this phase of inquiry. More specifically, when looking to published research for these answers, the introduction section of the research article will be most helpful as it lays out the research that supports and leads up to the current study.

- Phase II explores whether the intervention in question is appropriate for an individual with autism and whether the service provider is suitable. When looking to published research for these answers, two sections of an article will be most helpful: the method and discussion sections. The method section describes the participants. To the extent that an individual is similar to the participant in the study, it is reasonable to expect that he/she may have a similar response to that particular treatment. The discussion section of an article lists the contributions and limitations of the treatment and the study itself.
- Phase III describes assessing outcomes objectively and whether the risks are outweighed by the potential benefits. The results and discussion sections provide helpful information to answer these questions regarding target behaviors (often called the dependent variables), how they are measured, the amount of behavior change, and an analysis of the advantages and disadvantages. We hope it is clear to the reader that in the absence of published scientific evidence that a particular intervention is effective, consumers must be particularly cautious and these questions should be considered even more carefully.

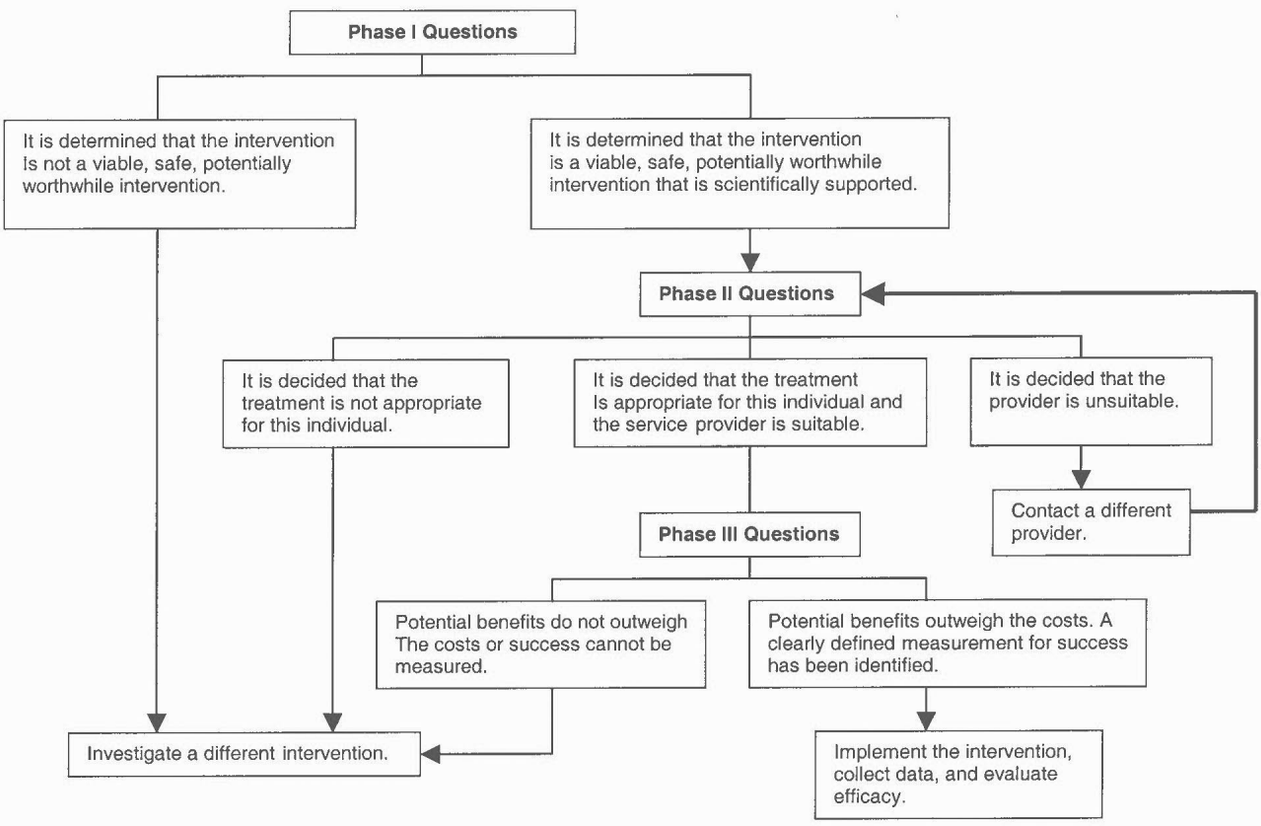

Figure 1. Decision-Making Flow Chart for Evaluating Alternative Interventions for Individuals with Autism

Phase I

Exploring the viability and appropriateness of a treatment approach

Research

- First and foremost, what research is available in the professional literature that confirms the effectiveness of this approach? Is there research that does not support the effectiveness of this approach?
- In the absence of published research supporting the effectiveness of this approach, how do the proponents of the approach justify their advocacy in the face of no published, scientific support? (See Green, 1996a)
- What percentage of individuals with autism has experienced positive effects with this treatment approach? Are there any characteristics that differentiate the individuals who experience positive effects from those who do not?
- How important are these positive effects? Are they statistically significant (i.e., data obtained in a scientific investigation to suggest that the desired change is not due to chance)? Are they clinically significant (i.e.,observations suggest a noticeable and desirable change in one or more important area of concern)?
- Do the results appear in published research, or are they presented as estimates in a case study or narrative report? What is the size of the group upon which these estimates are based? If they are estimates, who are they based upon?
- Does the published literature represent objective, empirical research (i.e., scientifically driven and data- based)? Or is it descriptive research that describes someone's impressions over time?
- What is the theory/rationale that drives this treatment approach? Does this theory make intuitive sense? Does this theory have scientific support?
- Are there individuals examining this approach who are committed to science-based research? How many researchers are currently investigating this treatment approach?
- How can this supporting literature be obtained?

Treatment

- What areas of functioning and specific behaviors are being targeted by this approach? In other words, how exactly does this treatment impact upon individuals with autism?
- How does this treatment approach work? Is there a planned and documented sequence of assessment and intervention strategies?
- How will skill gains made in treatment sessions generalize to everyday settings in a functional manner?
- What are the risks and benefits of this treatment approach? Do the potential benefits outweigh the risks? Are there other approaches that may provide the same benefits with fewer risks?
- Are there adverse effects associated with this treatment approach?
- How long has this approach been available?
- Are there multiple service providers with whom this treatment approach can be discussed?

If this treatment approach appears to be a viable, safe, potentially worthwhile intervention that has sufficient scientific support, then Phase II questions should be explored. If unsatisfactory responses are obtained, if multiple incomplete responses are offered, or appropriate answers could not be located, then consumers are discouraged from pursuing the approach in question.

Phase II

Assessing the appropriateness of the intervention under the supervision of a specific service provider for a specific individual with autism

- Why is this specific individual with autism a good candidate for this treatment approach? Upon what information is this determination based (e.g., analysis of immune functioning, behavioral observation, data from blood work, standardized testing)?
- Does every individual with autism receive the exact same treatment? If not, how will this treatment be individually tailored and based on what factors? In other words, how can this treatment approach be adjusted to meet the needs of the specific individual?
- How does this approach fit in with the individual's existing treatment? Can it complement existing interventions? Is it compatible? Is it counterproductive or will it interfere with the existing treatment? In what ways? How can such interference be prevented, avoided, or minimized?
- What are the necessary credentials and experiences to carry out this treatment approach safely and effectively? Does the potential service provider have the necessary credentials and experiences to carry out this treatment approach safely and effectively?
- Is there a system of procedural safeguards providing oversight and accountability for this service provider in the case of malpractice? (Examples include licensing and certification boards.)
- How does this treatment approach as it is outlined in the available research literature differ from the actual treatment approach used by the service provider?
- How costly is this treatment approach for the specific individual? In terms of financial resources? In terms of time accessing services? In terms of disruption to other services? In terms of parental effort? In terms of impact on family life?
- What are the start-up expenses? What are the ongoing expenses? Will the expenses be covered by insurance? Will the expenses be covered by the school district (if the individual with autism is enrolled in school)? Are there external sources of funding for this treatment approach?
- What is the parents' and caregivers' role in implementing or supporting this treatment approach? What support or oversight is needed?
- What is the school's role in implementing or supporting this treatment approach? What support or oversight is needed?

If it has been decided that this treatment approach may be appropriate for the specific individual with autism and a particular service provider is suitable to offer the treatment approach, then proceed to the Phase III questions. If the potential provider is not able to answer questions satisfactorily or does not have the necessary credentials or experiences, then another provider should be sought and Phase II questions should be reconsidered. If it appears that the individual with autism is not a suitable candidate, then consumers are encouraged to explore other approaches or continue their inquiry with another provider (to obtain a second opinion).

Phase III

Monitoring the implementation of the treatment and evaluating effectiveness

- How will success be measured for the specific individual?
- What specific areas of behavior or physiological functioning are being used to measure effectiveness? Have these areas been defined objectively, clearly, and concisely?
- What baseline data are requested by the service provider (i.e., information collected prior to an intervention in order to provide an objective standard for evaluating change)? This is an important question to ask because many service providers fall short in this area.
- Does the service provider discuss ongoing data collection? If not, how does the provider anticipate making an objective judgment about the success of the intervention in the absence of data?
- Does this treatment approach lend itself to a reversal (i.e., the treatment is briefly discontinued to see if the rate of target behavior returns to original levels)?
- How will the service provider measure the effectiveness of the intervention if there are concurrent interventions that may be targeting the same areas? How can unique contributions of the concurrent interventions be determined?
- Do the potential positive benefits outweigh the costs?
- Are there any potential side effects that should be anticipated for this individual? How should the side effects be managed? Which side effects warrant a call to the service provider? Which side effects warrant immediate discontinuation of the treatment?
- What will the length of this intervention be for the individual? What time period is necessary for this approach to begin to show positive effects?
- How frequently does the individual need to be seen by the service provider? What will the re-evaluation involve?
- At what point can one expect to stop this intervention? How will it be discontinued or faded?
- How frequently does the parent need to communicate with the service provider? What kind of information should the parent be reporting to the service provider?
- What should the school's role in monitoring this treatment approach be, if any? Would there be any benefit to restricting information about the intervention to only a select few staff persons (i.e., in order to minimize a biased evaluation of change)?

Conclusion

The above list of questions is not intended to be exhaustive, nor is it necessary to use the entire list when exploring alternatives. Instead, this list is provided in the hopes of expanding the range of considerations available to parents and caregivers when pursuing any treatment approach, even an approach that enjoys significant scientific support such as ABA. Parents who possess greater knowledge and a framework for evaluating treatments can feel more confident in making sound treatment decisions. As consumers of these services and perhaps the strongest advocates for their children's safety and well-being, parents have not only the right, but also the responsibility to protect their children. Parents and caregivers should be informed as to what they can expect from any given treatment and should be knowledgeable about whether there are any potential risks associated with that treatment.

Professionals who offer or market interventions to individuals with autism have the obligation to fully explain their treatment methods, to clearly identify the nature and range of possible treatment effects, and to provide a means for evaluating the effectiveness of their interventions objectively. Professionals should not be offended when asked such questions concerning their services, and parents should not be made to feel intimidated for seeking such information.

We look forward to the day when parents need not work so hard at sifting though the enormous number of approaches available and when service providers have a broader array of scientifically-validated procedures to draw upon when addressing the many needs of children with autism. It is hoped that by empowering parents with the tools needed to negotiate the maze of interventions and to be more knowledgeable consumers, the quality of services available to individuals with autism will be enhanced and the road to effective treatment will be clearer.

[Authors' Note: The authors would like to thank Rebecca Hernandez for feedback on the current version of this manuscript and Lynn Faerber, Eileen Hopkins, Mary Jane Weiss, Peter Gerhardt, Sandra Harris, and Erika Deusinger for their feedback on an earlier version. In addition, the first author would also like to thank the Human Rights Committee of the Devereux Millwood Learning Center for input on a preliminary list of the questions for consideration contained herein.]

Endnotes

1. Crosland, Zarcone, Lindauer, Valdovinos, Zarcone, Hellings & Schroeder, 2003; Green, 1996a; Green, 1996b

2. Assumpcao, 1998; Cook, 2001; Courchesne, 1995; Courchesne, Carper, & Akshoomoff, 2003; Eigsti & Shapiro, 2003; Kemper & Bauman, 1993; Kemper & Bauman, 1998; Mazzocco, Kates, Baumgardner, Freund, & Reiss, 1997; Mesibov, Adams, & Klinger, 1997; Nicolson & Szatmari, 2003; Shastri, 2003

3. Barnard, Young, Pearson, Geddes, & O' Brien, 2002; Cohen, Ihrig, Lott, & Kerrick, 1998; Cook, Rowlett, Jaselskis, & Leventhal, 1992; DeLong, Teague, & McSwain, 1998; Fatemi, Realmuto, Khan, & Thuras, 1998; Gringas, 2000; Hammock, Schroeder, Levin, 1995; Langworthy-Lam, Aman, & Van Bourgondien, 2002; Kwok, 2003; McDougle, Holmes, Carlson, Pelton, Cohen, & Price, 1998; Sweeney, Forness, & Levitt, 1998

4. Matson, Benavidez, Compton, Paclawskyj, & Baglio, 1996; McClannahan, MacDuff, & Krantz, 2002; Rossenwasser & Axelrod, 2001; Rossenwasser & Axelrod, 2002

5. Anderson, Avery, DiPietro, Edwards, & Christian, 1987; Birnbrauer & Leach, 1993; Eikeseth, Smith, Jahr, & Eldevik, 2002; Fenske, Zalenski, Krantz, & McClannahan, 1985; Harris & Handleman, 2000; Harris, Handleman, Gordon, Kristoff, & Fuentes, 1991; Lovaas, 1987; Luiselli, Cannon, Ellis, & Sisson, 2002; Smith, Groen, & Wynn, 2000

6. Collaborative Work Group on Autistic Spectrum Disorders, 1997; Maine Administrators of Services for Children with Disabilities Autism Taskforce, 1999; New York State Department of Health, 1999; U.S. Department of Health and Human Services, 1999

7. Buchanan & Weiss, in press; Fovel, 2002; Harris & Weiss, 1998; Koegel & Koegel, 1995; Leaf & McEachin, 1999; Lovaas, 2003; Maurice, Green, & Luce, 1996; Maurice, Green, & Foxx, 2001

8. Freeman, 1997; Maurice, Green and Luce, 1996

9. For more information on professional standards, you are referred to the Consumer Guidelines published by the Autism Special Interest Group of the Association for Behavior Analysis (1998) at www.abainternational.org and the Behavior Analyst Certification Board www.bacb.com. A revised version of the Consumer Guidelines will be available in the summer of 2004

10. Green, 1996a; Green, 1996b; Smith, 1996; Maine Administrators of Services for Children with Disabilities Autism Taskforce, 1999; New York State Department of Health, 1999; U.S. Department of Health and Human Services, 1999

11. Fox, 1999

12. American Psychological Association, 1994; Cardinal, Hanson, & Wakeham, 1996; Green & Shane, 1994; Jacobson, Mulick, & Schwartz, 1995; Wheeler, Jacobson, Paglieri, & Schwartz, 1993

13. American Academy of Pediatrics, 1998; American Speech-Language-Hearing Association, 2004; Gravel, 1994

14. Arendt, MacLean, Baumeister, 1988; Hoehn & Baumeister, 1994; Mason & Iwata, 1990; Ottenbacher & Short, 1985

Appendix A

Sample Form to Evaluate Treatments for Autism

Phase I

Treatment approach

Does this approach have empirical support in peer-reviewed journals? ☐ yes ☐ no

How can I obtain this and other relevant literature? _____

_____

According to this literature, what percentage of individuals makes objective and meaningful progress? _____

_____

How does this treatment work? _____

_____

How can I obtain a written copy of the procedures? _____

_____

Are there risks or adverse side effects? _____

_____

What are the criticisms and limitations of this approach? _____

_____

How do the proponents respond? _____

_____

Phase II

Specific service provider for a specific individual

How will the treatment be individualized? _____

_____

What are the necessary experiences and credentials to carry out this treatment approach safely and effectively?

_____

What experiences and credentials does this service provider have (years of supervised and independent experience, number of individuals with autism, types of behaviors treated, etc.)? _____

_____

What mechanisms are in place for oversight of this service provider such as a licensing board, professional board, or provider agency? _____

_____

What are the costs in terms of finances, time, materials, etc.? _____

_____

What roles do the parents, other family members, and school personnel play? _____

_____

Appendix A

Sample Form to Evaluate Treatments for Autism

Phase III

Monitoring implementation and evaluating effectiveness

How will progress or lack thereof be evaluated?_____

_____

Are target behaviors stated in observable and measurable terms?_____

_____

Are the assessment strategies logical and thoroughly described? ☐ yes ☐ no

Are the intervention strategies logical and thoroughly described? ☐ yes ☐ no

How will gains in treatment generalize to everyday settings?_____

_____

How will we know when to change specific and general strategies? _____

_____

How long is the individual expected to need treatment?_____

_____

With this service provider? _____

Others? _____

How often should the parent and the service provider communicate?_____

_____

What types of information would be helpful to the service provider? _____

_____

Tables

Table 1

Partial list of peer-reviewed journals

While not an exhaustive list, the following journals are well-regarded sources of information. Publication in these journals involves a process known as peer review in which a study is evaluated, critiqued and eventually determined by a group of experts to be scientifically and clinically valuable.

- *Analysis and Intervention in Developmental Disabilities*
- *Analysis of Verbal Behavior*
- *Autism*
- *Behavioral Interventions*
- *Behavior Therapy*
- *Child and Family Behavior Therapy*
- *Focus on Autism and Developmental Disorders*
- *Journal of Applied Behavior Analysis*
- *Journal of the American Academy of Child and Adolescent Psychiatry*
- *Journal of Autism and Developmental Disorders*
- *Journal of the Association for People with Severe Handicaps*
- *Journal of Consulting and Clinical Psychology*
- *Journal of Positive Behavior Interventions*
- *Journal of Speech and Hearing Disorders*
- *Research in Developmental Disabilities*

Table 2

Partial list of associations that provide information about autism treatment

American Occupational Therapy Association	www.aota.org
American Speech-Language-Hearing Association	www.asha.org
Association for Behavior Analysis (ABA) Autism Special Interest Group Parent-Professional Partnership Special Interest Group State, Regional, and International Chapters of ABA	www.abainternational.org www.autismsig.org www.pppsig.org
Association for Science in Autism Treatment (ASAT)	www.asatonline.org
Autism New Jersey	www.autismnj.org
Autism Speaks	www.autismspeaks.org
Behavior Analyst Certification Board (BACB)	www.bacb.com
Cambridge Center for Behavioral Studies	www.behavior.org
The Interdisciplary Council on Developmental and Learning Disorders	www.icdl.org
Organization for Autism Research (OAR)	www.researchautism.org

References

American Academy of Pediatrics (1998). Auditory integration training and facilitated communication for autism. *Pediatrics, 102,* 431- 433.

American Psychological Association (1994). Resolution on facilitated communication by the American Psychological

Association. Adopted in Council, August 14, 1994, Los Angeles, California.

American Speech-Language-Hearing Association. (2004). Auditory integration training. *ASHA Supplement, 24*, in press.

Anderson, S. R., Avery, D. L., DiPietro, E. K., Edwards, G. L., & Christian, W. P. (1987). Intensive home-based early intervention with autistic children. *Education and Treatment of Children, 10*, 352-366.

Arendt, R. E., MacLean, W. E., & Baumeister, A. A. (1988). Critique of sensory integration therapy and its application in mental retardation. *American Journal on Mental Retardation, 92,* 401-411.

Assumpcao, F. B. (1998). Brief report: A case of chromosome 22 alteration associated with autistic syndrome. *Journal of Autism and Developmental Disorders, 28*, 253-256.

Barnard, L., Young, A. H., Pearson, J., Geddes, J., & O'Brien, G. (2002). A systematic review of the use of atypical antipsychotics in autism. *Journal of Psychopharmacology, 16,* 93-101.

Birnbrauer, J.S., & Leach, D. J. (1993). The Murdoch Early Intervention Program after 2 years. *Behaviour Change, 10,* 63-74.

Buchanan, S. M., & Weiss, M. J. (2010). *Applied behavior analysis and autism: An introduction*. Robbinsville, NJ: Autism New Jersey.

Cardinal, D. A., Hanson, D., & Wakeham, J. (1996). Investigation of authorship in facilitated communication. *Mental Retardation, 34*, 231-242.

Collaborative Work Group on Autistic Spectrum Disorders. (1997). Best practices for designing and delivering effective programs for individuals with autism spectrum disorders. Sacramento, CA: California Department of Education and Developmental Services.

Cohen, S. A., Ihrig, K., Lott, R. S., & Kerrick, J. M. (1998). Risperidone for aggression and self-injurious behavior in adults with mental retardation. *Journal of Autism and Developmental Disorders, 28*, 229-233.

Cook, E. H. (2001). Genetics of autism. *Child and Adolescent Psychiatric Clinics of North America, 10,* 333-350.

Cook, E. H., Rowlett, R., Jaselskis, C., & Leventhal, B. L. (1992). Fluoxetine treatment of children and adults with autistic disorder and mental retardation. *Journal of the American Academy of Child and Adolescent Psychiatry, 31,* 739-745.

Courchesne, E. (1995). New evidence of cerebellar and brainstem hypoplasia in autistic infants, children, and adolescents: The MR imaging study by Hashimoto and colleagues. *Journal of Autism and Developmental Disorders, 25*, 19-22.

Courchesne, E., Carper, R., & Akshoomoff, N. (2003). Evidence of brain overgrowth in the first year of life in autism. *Journal of the American Medical Association, 290,* 337-344.

Crosland, K. A., Zarcone, J. R., Lindauer, S. E., Valdovinos, M. G., Zarcone, T. J., Hellings, J. A., & Schroeder, S. R. (2003). Use of functional analysis methodology in the evaluation of medication effects. *Journal of Autism and Developmental Disorders, 33*, 271-279.

DeLong, G. R., Teague, L. A., McSwain, K. M. (1998). Effects of fluoxetine treatment in young children with idiopathic autism. *Developmental Medicine and Child Neurology, 40,* 551-562.

Eigsti, I. M., & Shapiro, T. (2003). A systems neuroscience approach to autism: Biological, cognitive, and clinical perspectives. *Mental Retardation and Developmental Disabilities Research Review, 9*, 205-215.

Eikeseth, S., Smith, T., Jahr, E., & Eldevik, S. (2002). Intensive behavioral treatment at school for 4- to 7-year-old children with autism: A 1-year comparison controlled study. *Behavior Modification, 26*, 49-68.

Fatemi, S. H., Realmuto, G. M., Khan, L., & Thuras, P. (1998). Fluoxetine in treatment of adolescent patients with autism: A longitudinal open trial. *Journal of Autism and Developmental Disorders, 28*, 303-307.

Fenske, E. C., Zalenski, S., Krantz, P. J., & McClannahan, L. E. (1985). Age at intervention and treatment outcome for autistic children in a comprehensive intervention program. *Analysis and Intervention in Developmental Disabilities, 5*, 7-31.

Fovel, T. J. (2002). T*he ABA program companion: Organizing quality programs for children with autism and PDD.* New York, New York: DRL Books.

Fox, A. M. (1999). Viewpoint: Sensory integration therapy in autism. *Science in Autism Treatment, Fall 1999*.

Freeman, B. J. (1997). Guidelines for evaluating intervention programs for children with autism. J*ournal of Autism and Developmental Disorders, 27*, 641-651.

Gravel, J. S. (1994). Auditory integrative training: Placing the burden of proof. *American Journal of Speech and Language Pathology, 3*, 25-29.

Green, G. (1996a). Evaluating claims about treatments for autism. In C. Maurice (Ed.), G. Green, & S. C. Luce (Co-eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 15-28). Austin, TX: PRO-ED.

Green, G. (1996b). Early behavioral intervention for autism: What does research tell us? In C. Maurice (Ed.), G. Green, & S. C. Luce (Co-eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 29-44). Austin, TX: PRO-ED.

Green, G, & Shane, H. (1994). Science, reason, and facilitated communication. T*he Journal of the Association for Persons with Severe Handicaps, 19*, 151-172.

Gringras, P. (2000). Practical paediatric psychopharmacological prescribing in autism: The potential and the pitfalls. *Autism, 4*, 229-247.

Hammock, R. G., Schroeder, S. R., & Levine, W. R. (1995). The effect of clozapine on self-injurious behavior. *Journal of Autism and Developmental Disorders, 25*, 611-626.

Harris, S. L., & Handleman, J. S. (2000). Age and IQ at intake as predictors of placement for young children with autism: A four- to six- year follow-up. *Journal of Autism and Developmental Disorders, 30,* 137- 142.

Harris, S. L., Handleman, J. S., Gordon, R., Kristoff, B., & Fuentes, F. (1991). Changes in cognitive and language functioning of preschool children with autism. *Journal of Autism and Developmental Disorders, 21,* 281-290.

Harris, S. L., & Weiss, M. J. (1998). R*ight from the start: Behavioral intervention for young children with autism.* Baltimore, MD: Woodbine House.

Hoehn, T. P., & Baumeister, A. A. (1994). A critique of the application of sensory integration therapy to children with learning disabilities. *Journal of Learning Disabilities, 27,* 338-350.

Jacobson, J. W., Mulick, J. A., & Schwartz, A. A. (1995). A history of facilitated communication: Science, pseudoscience, and antiscience: Science working group on facilitated communication. *American Psychologist, 50*, 750-765.

Kemper, T. L., & Bauman, M. (1993). The contribution of neuropathologic studies to the understanding of autism. *Neurologic Clinics, 11*, 175-187.

Kemper, T. L., & Bauman, M. (1998). Neuropathology of infantile autism. J*ournal of Neuropathology and Experimental Neurology, 57,* 645-652.

Koegel, R. L., & Koegel, L. K. (Eds.) (1995). *Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities.* Baltimore, MD: Paul Brookes Publishing Company.

Kwok, H. W. (2003). Psychopharmacology in autism spectrum disorders. *Current Opinion in Psychiatry, 16,* 529-534.

Langworthy-Lam, K. S., Aman, M. G., & Van Bourgondien, M. E. (2002).Prevalence and patterns of use of psychoactive medicines in individuals with autism in the Autism Society of North Carolina. *Journal of Child and Adolescent Psychopharmacology, 12,* 311-321.

Leaf, R., & McEachin, J. (1999). *A work in progress: Behavior management strategies & a curriculum for intensive behavioral treatment of autism.* New York, NY: DRL Books.

Lovaas, O. I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology, 55,* 3-9.

Lovaas, O. I. (2003). *Teaching individuals with developmental delays: Basic intervention techniques*. Austin, TX: PRO-ED.

Luiselli, J. K., Cannon, B. O., Ellis, J. T., & Sisson, R. W. (2000). Home-based behavioral interventions for young children with autism/pervasive developmental disorder: A preliminary evaluation of outcome in relation to child age and intensity of service delivery. *Autism, 4,* 426-438.

MADSEC Autism Taskforce. (1999). *Executive summary*. Portland, ME: Department of Education, State of Maine.

Mason, S. A., & Iwata, B.A. (1990). Artifactual effects of sensory-integrative therapy on self-injurious behavior. J*ournal of Applied Behavior Analysis, 23,* 361-370.

Matson, J. L., Benavidez, D. A., Compton, L. S., Paclawskyj, T., & Baglio, C. (1996). Behavioral treatment of autistic persons: A review of research from 1980 to the present. *Research in Developmental Disabilities, 17,* 433-456.

Maurice, C. (Ed.), Green, G., & Luce, S. (Co-eds.). (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals*. Austin, TX: PRO-ED.

Maurice, C. (Ed.), Green, G., & Foxx, R. M. (Co-eds.). (2001). *Making a difference: Behavioral intervention for young children with autism.* Austin, TX: PRO-ED.

Mazzocco, M. M., Kates, W. R., Baumgardner, T. L., Freund, L. S., & Reiss, A. L. (1997). Autistic behaviors among girls with fragile x syndrome. *Journal of Autism and Developmental Disorders, 27*, 415-435.

McClannahan, L. E., MacDuff, G. S., & Krantz, P. (2002). Behavior analysis and intervention for adults with autism. *Behavior Modification, 26*, 9-26.

McDougle, C. J., Holmes, J. P., Carlson, D. C., Pelton, G. H., Cohen, D. J., & Price, L. H. (1998). A double-blind, placebo-controlled study of risperidone in adults with autistic disorder and other pervasive developmental disorders. *Archives of General Psychiatry, 55*, 633-641.

Mesibov, G. B., Adams, L. W., & Klinger, L. G. (1997). *Autism: Understanding the disorder.* New York: Plenum Press.

Montee, B. B., Miltenberger, R. G., & Wittrock, D. (1995). An experimental analysis of facilitated communication. *Journal of Applied Behavior Analysis, 28*, 189-200.

New York State Department of Health. (1999). *Clinical practice guidelines: The guideline technical report – Autism/pervasive developmental disorders, assessment and intervention.* Albany, NY: Early Intervention Program, New York State Department of Health.

Nicolson, R., & Szatmari, P. (2003). Genetic and neurodevelopmental influences in autistic disorder. *Canadian Journal of Psychiatry, 48,* 526-537.

Ottenbacher, K., & Short, M. A. (1985). Sensory integrative dysfunction in children: A review of theory and treatment. *Advances in Developmental and Behavioral Pediatrics, 6*, 287-329.

Rosenwasser, B., & Axelrod, S. (2001). The contributions of applied behavior analysis to the education of people with autism. *Behavior Modification, 25,* 671-677.

Rosenwasser, B., & Axelrod, S. (2002). More contributions of applied behavior analysis to the education of people with autism. *Behavior Modification, 26*, 3-8.

Shastry, B. S. (2003). Molecular genetics of autism spectrum disorders. *Journal of Human Genetics, 48*, 495-501.

Smith, T. (1996). Are other treatments effective? In C. Maurice (Ed.), G. Green, & S. C. Luce (Co-eds.), *Behavioral intervention for young children with autism: A manual for parents and professionals* (pp. 45-59). Austin, TX: PRO-ED.

Smith, T., Groen, A. D., & Wynn, J. W. (2000). Randomized trial of intensive early intervention for children with pervasive developmental disorder. *American Journal on Mental Retardation, 105*, 269-285.

Sweeney, D. P., Forness, S. R., & Levitt, J. G. (1998). An overview of medications commonly used to treat behavioral disorders associated with autism, Tourette syndrome, and pervasive developmental disorders. *Focus on Autism and Other Developmental Disabilities, 13,* 144-150.

U.S. Department of Health and Human Services. (1999). *Mental health: A report of the surgeon general.* Rockville, MD: U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, National Institutes of Health, National Institute of Mental Health.

Wheeler, D. L., Jacobson, J. W., Paglieri, R. A., & Schwartz, A. A. (1993). An experimental assessment of facilitated communication. *Mental Retardation, 31,* 49-60.

About the Authors

Dr. David A. Celiberti received his Ph.D. in clinical psychology from Rutgers University in 1993 and his certification in behavior analysis in 2000. He is in private practice and provides consultation to schools and agencies in the U.S. and Canada. He has authored several articles in professional journals and frequently presents at regional, national, and international conferences. He has taught courses related to ABA at both the undergraduate and graduate levels, supervised doctoral students providing behavior therapy and other clinical services, and conducted research in the areas of Applied Behavior Analysis, family intervention, and autism. Dr. Celiberti is served four terms as President of the Autism Special Interest Group (SIG) for the Association for Behavior Analysis. He also founded the Parent-Professional Partnership SIG and is serving as its first President.

Dr. Suzanne M. Buchanan received her Psy.D. in clinical psychology from Long Island University and her certification in behavior analysis in 2000. She is currently the Director of Clinical Services at Autism New Jersey, a nonprofit autism agency in New Jersey. In this position, Dr. Buchanan has an active role in state autism task forces, parent education and support groups, professional workshops and consultations, staff supervision, and agency publications. She has fourteen years of experience working with individuals with autism, their parents and their siblings in home and school settings. As a member of the Association for Behavior Analysis and the first Vice President of the Parent-Professional Partnership Special Interest Group, she is devoted to increasing parents' access to accurate information about autism and effective treatment.

Dr. Felicia N. Bleecker received her Psy.D. in clinical psychology from Rutgers University and completed a Fellowship at the School of Medicine at Yale University. Since receiving her degree, she continues to work with children, adolescents, and families in private practice and school settings. With several years of training at The Douglass Developmental Disabilities Center in New Brunswick, New Jersey, Dr. Bleecker continues to work with children with autism both individually and in social skills groups. She also supports children with autism as a consultant for school-based placement and intervention.

Dr. David S. Kreiss received his Psy.D. in clinical psychology from the Graduate School of Applied and Professional Psychology at Rutgers University in 2003. He has a Master's degree in Child Development from Tufts University. As a graduate student, he worked as a Behavioral Consultant at The Douglass Developmental Disabilities Center where he instructed an undergraduate course in ABA and worked with children with autism. Dr. Kreiss is in private practice in Metuchen and Red Bank, New Jersey, and has presented at several workshops for the autism community.

Dr. David Rosenfeld received his Psy.D. in clinical psychology from the Graduate School of Applied and Professional Psychology at Rutgers University. He is a school psychologist at the Lakeland-Andover School, a private high school for adolescents with emotional and behavioral disturbances located in Lafayette, New Jersey. Dr. Rosenfeld spent several years of his doctoral training working as a Behavioral Consultant at The Douglass Developmental Disabilities Center.