

# AUTISM

AND RELATED DEVELOPMENTAL DISABILITIES

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## Alternative Treatments

### INSIDE THIS ISSUE:

### Special Section: Alternative Treatments 1

#### Identifying Evidence Based Treatments

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Interview	9
Program Description	14
Article Synopses and Book Review	17
<b>ABA SIG NEWS</b>	<b>25</b>

#### Introduction: Evidence Based Treatment

In the broad field of clinical psychology, there has been increased interest in and emphasis on the use of empirically supported treatments for psychological disorders, including autism. Researchers and clinicians have taken steps to identify the comprehensive programs and focal methods that are most effective in treating autism. We will review various definitions of evidence-based treatment, along with the criteria used to evaluate treatments. Several strategies in applied behavior analysis (ABA) will be highlighted, as they clearly have the largest body of evidence supporting their effectiveness. In addition, a variety of strategies that are not empirically validated, but which are commonly used, will be reviewed. Finally, recommendations for both professionals advising consumers and for consumers navigating treatment decisions will be delineated.

#### Individuals with Autism

Guidelines have been developed to help caregivers for individuals with autism identify those research studies that offer the strongest support for a given treatment (Lonigan, Elbert, & Johnson, 1998; New York State Department of Health, Early Intervention Program, 1999; National Research Council, 2001). Such guidelines, however, do not outline clear delineations of treatments as either evidence based or non-evidence based. The multiple guidelines that currently exist describe varying levels of scientific strength and support on which treatments may be based. This continuum ranges from the broad identification of science to the more specific identification of empirically supported treatment.

#### Science, Pseudoscience, and Antiscience

When examining the evidence for the effectiveness of an intervention for individuals with autism, a distinction can first be made between what is clearly science, and what is not. To identify therapies that are evidence based, it is helpful to ensure that the elements of science and the scientific method have been used to demonstrate support for the effectiveness of a given intervention. Science is based in part on (1) the direct and objective observation of measurable events, (2) a systematic manipulation of conditions, (3) procedures that rule out alternative explanations for results, and (4) replication of the results (Green, 1996). In contrast, pseudoscience promotes specific phenomena without the use of the scientific method and without providing evidence of efficacy or effectiveness (Green, 1996). While scientific findings rest on the solid base of the scien-



tific method, pseudoscience relies heavily on the use of persuasive marketing that appeals to consumers. Such marketing generally involves the use of scientific jargon and testimonies by supposed experts.

An even more extreme phenomenon, antiscience, comprises the body of treatments that rejects the use of scientific methods altogether (Green, 1996). In contrast to pseudoscience, antiscience demonstrates a complete disregard for any type of data and suggests that empirical testing of the treatment is a violation of the treatment. Interventions supported by antiscience are based on belief alone.

While these basic definitions are helpful to begin an evaluation of the evidence for an intervention, a more in-depth review of the components of science will further delineate the differences between science, pseudoscience, and antiscience. The first distinction concerns data collection procedures. Science relies on the objective observation and measurement of observable events. Such measurement is accomplished using operational definitions, by which phenomena/treatments are defined in observable terms such that the use of the treatment and the measurement of the phenomena are unbiased and objective (Green, 1996; Cooper, Heron, & Heward, 2006). In general, scientific investigations are conducted by professionals who are well-trained in the implementation of the treatment and the data collection method, and who are often unaware of the hypotheses that the research is designed to address (Green, 1996). Science is designed to reduce the likelihood of bias influencing the results of the research. In pseudoscience and antiscience, treatments are supported by testimony, anecdotal reports, and subjective impressions, rather than on observed and measured phenomena.

Another difference between science and pseudoscience or antiscience is the strong commitment of science to ensuring that confounding variables are not responsible for the apparent effectiveness of the intervention. Science makes use of comparative research, in which the target treatment is compared to other treatments or to a lack of treatment to ensure that other variables—such as the passage of time or significant events in the environment—are not responsible for the observed effects. Scientific research is controlled to ensure that the treatment variables are responsible for any observable change, rather than external variables that may impact the treatment effects (Green, 1996; Cooper, Heron, & Heward, 2006). In addition, external validity is maintained by assessing the generalization of treatment effects across settings. In contrast, pseudoscience approaches are often non-comparative, relying only on indirect reports or pre-post measures in which the same child is evaluated before and after treatment. In these instances, extraneous variables may be responsible for changes in behavior, yet they are infrequently cited as possible explanatory variables by authors in such publications (Green, 1996).

It is relatively easy to educate consumers to differentiate between science and pseudoscience and antiscience. However, further discrimination is required to define “evidence based treatment” within the more global area of science. Researchers and clinicians have been struggling with the degree of support required for a treatment to be considered evidence based. Perhaps unintentionally, they have created a continuum of degrees of evidence by which treatments can be assessed. The range of the quality of support for various treatments extends from those that are based on only one well-conducted research study to those that rest on a large body of convincing evidence. Those that are based on the most convincing evidence may be called “empirically supported treatments,” while a variety of somewhat less convincingly supported treatments have enough evidence accrued to still be considered evidence based.

### **Empirically Supported Treatments**

In line with the increased focus on and need for evidence based treatments among for children with psychological disorders, Division 12 of the American Psychological Association assembled the Task Force on Promotion and Dissemination of Psychological Procedures to develop guidelines by which a treatment could be identified as an “empirically supported treatment.” Lonigan, Elbert, and Johnson (1998) outline criteria for both “well-established interventions” (p. 141) and “probably efficacious treatments” (p. 141). Well-established interventions for childhood disorders are supported by at least two well-conducted group design studies implemented by at least two different investigators that indicate that the treatment is either more effective than pill placebo or an alternative treatment, or is equivalent to previously established treatments evaluated in studies with adequate statistical power.

Single-subject research designs, used by many researchers within the field of behavior analysis, can also be used to measure the effects of treatment on individuals. In these designs, researchers use visual representations of the measurement of behavior to compare an individual’s level of behavior prior to and following treatment to determine the effectiveness of the intervention (Green, 1996). Distinct single-subject designs are used to ensure that the results of the treatment are not due to external, or confounding, variables. Single-subject design studies often report data for a small number of participants, and researchers examine the effects of treatment on each individual (Cooper et al., 2006).

Within applied behavior analysis—and particularly in the field of autism—researchers utilize single-

subject design to examine the effects of treatment at the level of the individual. The guidelines developed by Lonigan et al. (1998) account for the fact that many treatments for children are supported by single-subject design research. The authors suggest that a body of evidence comprised of more than nine single-case design studies that use good experimental design, utilize treatment manuals, and clearly specify sample characteristics may meet the definition of well-established evidence. They also suggest that these single-case design studies should compare the target intervention to an alternative treatment.

Probably efficacious treatments are supported by either (1) two studies indicating that the studied treatment is more effective than a no-treatment control group, (2) two group-design studies that meet the criteria mentioned above for well-established interventions but are conducted by the same investigator offer support for the treatment, or (3) a series of 3 or more single-subject design studies that fit the criteria described above support the effectiveness of the treatment (Lonigan, Elbert, & Johnson, 1998).

The criteria for well-established treatments and probably efficacious treatments, as described by Lonigan et al. (1998), are difficult to attain. While many focal treatments that target specific skill deficits within the population of individuals with autism (e.g., motor deficits, communication deficits, social deficits) meet the above criteria, no comprehensive treatment program—a program that seeks to improve the overall functioning of individuals with autism—currently meets Lonigan et al’s criteria for an empirically supported treatment (Rogers, 1998). Rogers identifies several impediments to meeting these criteria, including the challenge of designing a research study or series of research studies to examine the efficacy of a comprehensive treatment for autism. While treatment for many childhood disorders can be disseminated over a short period of time, comprehensive treatments for children with autism are much more time-consuming and labor-intensive. A comprehensive treatment for autism requires the implementation of a treatment delivered for 20 to 30 hours per week for at least 24 months to a minimum of 25 children. The assessments and the treatment would both require many hours of intervention and significant numbers of personnel. Furthermore, the use of control groups and random assignment creates both ethical and practical difficulties given the potential benefits and the importance of urgent intervention (Rogers, 1998).

Some organizations have developed guidelines to assist with these complex issues. While these guidelines are generally not as strict as those developed by Lonigan et al. (1998), they do help to identify comprehensive evidence based effective treatments specifically for individuals with autism. Such guidelines for evidence-based treatment are especially necessary in the field of autism, where interventions based in pseudoscience and antiscience are numerous and commonly utilized.

### **Categorizing Research on the Treatment of Autism**

#### **Study Characteristics – Group Design**

	<b>Participants</b>	<b>Design</b>	<b>Additional Elements</b>
<b>Strong</b>	Adequate group sizes to establish statistical power and effect size	Comparison of treatment to placebo or established treatment	Random assignment, raters blind to conditions, evaluation of generalization, maintenance, and social validity
<b>Adequate</b>	Adequate group sizes to establish statistical power and effect size	Comparison of treatment to no treatment or wait-list	Random assignment, raters blind to conditions, may not address generalization, maintenance or social validity
<b>Weak</b>	Insufficient groups for statistical analyses	Pre/post	No random assignment, raters not blind to conditions, no evaluation of generalization, maintenance or social validity

Study Characteristics – Single-Subject Design

	<b>Design</b>	<b>Analysis</b>	<b>Additional Elements</b>
<b>Strong</b>	Multiple-baseline design, alternating treatments design, reversal (ABAB) design, combination	3 or more demonstrations of the treatment effect (e.g., across subjects, behavior, settings)	Evaluation of generalization, maintenance, and social validity
<b>Adequate</b>	Multiple-baseline design, alternating treatments design, reversal (ABAB) design, combination	2 or more demonstrations of the treatment effect	Addresses at least one element of generalization, maintenance or social validity
<b>Weak</b>	Pre/post, case study	1 demonstration of the treatment effect	No evaluation of generalization, maintenance or social validity

**Navigating the Waters of Effective Intervention for Learners with Autism: How Parents and Practitioners Can Become Informed Consumers of Services**

Robert LaRue

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Autism is a complex disorder characterized by significant deficits in social reciprocity and communicative ability as well as the presence of repetitive behavior/restricted interests. Given the complex nature of autism, a wide variety of interventions have emerged. The number of interventions used for the treatment of autism is huge. Applied Behavior Analysis (ABA), sensory integration, specialized diets, pharmacological interventions, mercury detoxification procedures are among the most commonly-used interventions with learners on the autism spectrum. However, many of these treatments persist in the absence of scientific data supporting their use. This absence of data is particularly problematic for parents and practitioners who are trying to provide the best possible intervention for their learners with autism. The prospect of selecting an appropriate treatment for autism can be overwhelming for anyone with the vast amount of conflicting information available.

Most experts agree that the best first line of treatment is an intensive, coordinated program of special education and behavior management. Developmentally appropriate intervention programs generally include a language-based curriculum, systematic intervention to improve communication and social skills and a structured plan to address maladaptive behavior. Behavioral intervention strategies, such as ABA, have the most empirical support for their use. In addition, ABA has been endorsed by the U.S. Surgeon General (1999) and the National Institutes of Health (NIH). While behavioral approaches to autism have been shown to be effective, they tend to be labor intensive as compared to many non-behavioral approaches to treatment.

Non-behavioral treatments can generally be divided into two main categories: biological and non-biological interventions. Biological interventions include treatments such as Hyperbaric Oxygen Therapy (HBOT), vitamin therapy, specialized diets (e.g., gluten-casein free diets) and psychotropic medication. Non-biological interventions include treatments such as Sensory Integration Therapy (SIT), Facilitated Communication and Craniosacral Therapy. With the exception of psychotropic medication research, sound empirical evidence supporting the effectiveness of these interventions for learners with autism is sparse. However, several studies have shown that certain psychotropic medications (e.g., Risperdal) can decrease some aberrant behavior autism (e.g., impulsivity, aggression).

While behavioral intervention is a good, empirically-supported starting point, it does not necessarily preclude the use of alternative interventions. Rejecting other types of intervention without understanding and evaluating them is problematic for several reasons. First, the *absence* of supporting evidence is not the same as evidence *against* an intervention. One of the main problems with the new and emerging treatments for autism is that limited research has been done to either validate or invalidate these interventions. Complicating this further is the fact that scientific

journals do not typically publish negative research findings. In other words, research indicating that particular treatments are not effective may not be accepted for publication because of a journal's bias to only print positive findings. Another complicating factor is the individual variability of response to different treatments for autism. As mentioned previously, autism is a complex disorder with a variety of different etiologies that may affect response to treatment. Strategies may work for some learners and not others. It is important for practitioners to approach the intervention process with an objective mind. Rather than dismissing alternative approaches to intervention, practitioners should take to opportunity to study these interventions and systematically eliminate components that are not effective.

Alternative therapies are going to be part of the autism treatment landscape for the years to come. It is the responsibility of both parents **and** practitioners to become informed consumers of autism services. It is important to critically review the validity of proposed treatments, read the literature (peer-reviewed articles rather than testimonials or anecdotal reports) and look for scientific evidence of benefit, potential health risks, and financial or time cost of all treatments. While the temptation to "leave no stone unturned" may seem appealing, wasting precious time with ineffective interventions may prevent learners from maximizing their potential.

In addition to educating themselves about alternative interventions, practitioners and parents should critically evaluate the effectiveness of the intervention process. It is often the case that people do not use systematic designs to assess the effectiveness of alternative treatments. Implementing treatments in a reversal (ABAB) design or multi-element designs can provide valuable information regarding the efficacy of treatments.

In addition, a variety of behavioral measurement procedures, such as observational data coding, preference and reinforcer assessments, and functional analyses, can be viable ways to evaluate the effects of these interventions. Using behavioral measures for the purpose of evaluation can allow for testing some of these alternative interventions to determine if there is a clinically significant response. Such procedures could allow parents and practitioners to only use interventions that are effective and discontinue components that are ineffective. These measures can be used to determine if treatment effects generalize to different settings and also to monitor the occurrence of side effects.

In summary, there exists a wide variety of behavioral and non-behavioral intervention for learners on the autism spectrum. Some of these interventions have garnered empirical support (i.e., ABA, some psychotropic medications) while many have not been studied thoroughly enough to validate the effectiveness for use with learners with autism. Unfortunately, many treatments that are ineffective persist because they often promise miraculous results and are easy to use. The best solution is for parents and practitioners to educate themselves regarding these alternative therapies and critically evaluate the effectiveness of these interventions. In doing so, parents and practitioners can ensure the best possible intervention for their learners, prevent time from being wasted and can ultimately help others through the process by sharing their findings with others.

### **Controversial Treatments for Autism in the Popular Media**

Jennifer Wick and Tristram Smith

University of Rochester Medical Center

Children with autism spectrum disorder (ASD) often receive controversial treatments – interventions that are popular despite an absence of scientific or theoretical support. As many as one-third of all newly-diagnosed children with ASD participate in such treatments (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003). Many others commence a controversial treatment soon after they begin conventional therapies such as behavioral or educational services, and some undergo multiple ones (Smith & Antolovich, 2000), which may continue into adolescence (Witwer & Lecavelier, 2005). The use of controversial treatments for children with ASD is a long-standing issue (Rimland, 1964), and the number of different treatments and their rate of use have grown over time (Levy & Hyman, 2003). Reports in the public media may be one factor associated with the popularity of controversial treatments (Levy & Hyman, 2003).

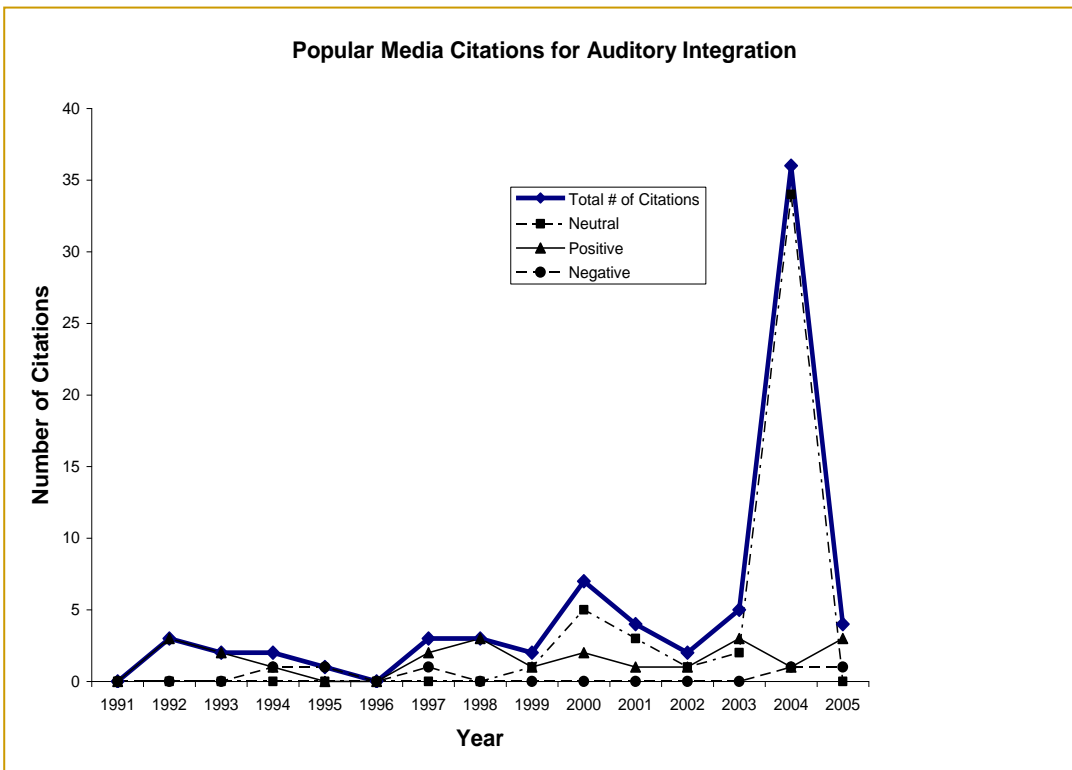
#### **Method**

The media database Lexis/Nexis was searched for full text reports each year from 1991 to 2005 on Facilitated Communication (FC), Auditory Integration, Sensory Integration, Gentle Teaching, Vitamin Therapy, Gluten-Free and Casein-Free (GfCf) Diet, Secretin, and Chelation. Each public report was rated as positive, negative, or neutral toward the treatment, and the basis for a positive or negative reference (e.g., case reports or research findings) was analyzed.

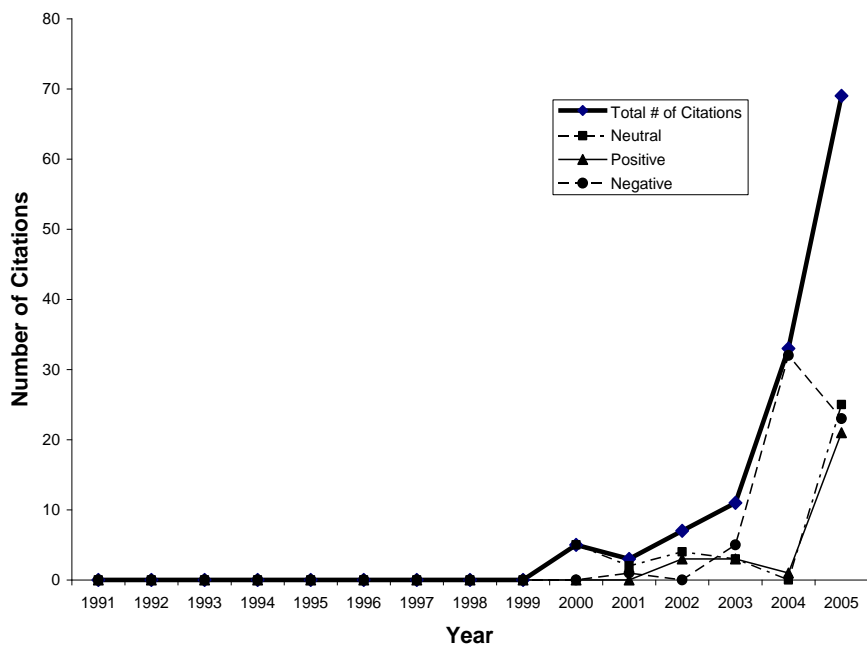
## Results

Overall, reports on controversial treatments were 29% positive, 44% neutral, and 27% negative. Most controversial interventions appeared suddenly and frequently in the media prior to any published research, including FC, Auditory Integration, Gentle Teaching, GfCf Diet, Secretin, and Chelation. Auditory Integration, Sensory Integration, Vitamin Therapy, and GfCf Diet had few negative reports (0-7%). Positive reports outnumbered negative ones for Facilitated Communication (39% positive, 29% negative) and Secretin (29% positive, 23% negative). Negative reports predominated only for Chelation (48% negative) and Gentle Teaching (33%). Negative reports usually cited anecdotal evidence of adverse effects rather than scientific studies. Public reports of each controversial treatment increased from year to year. From 1991 to 1998, sensorimotor and relationship therapies received more references than biomedical treatments, whereas the reverse was true subsequently. Both positive and negative media accounts were based primarily on anecdotal reports and case studies rather than on research findings.

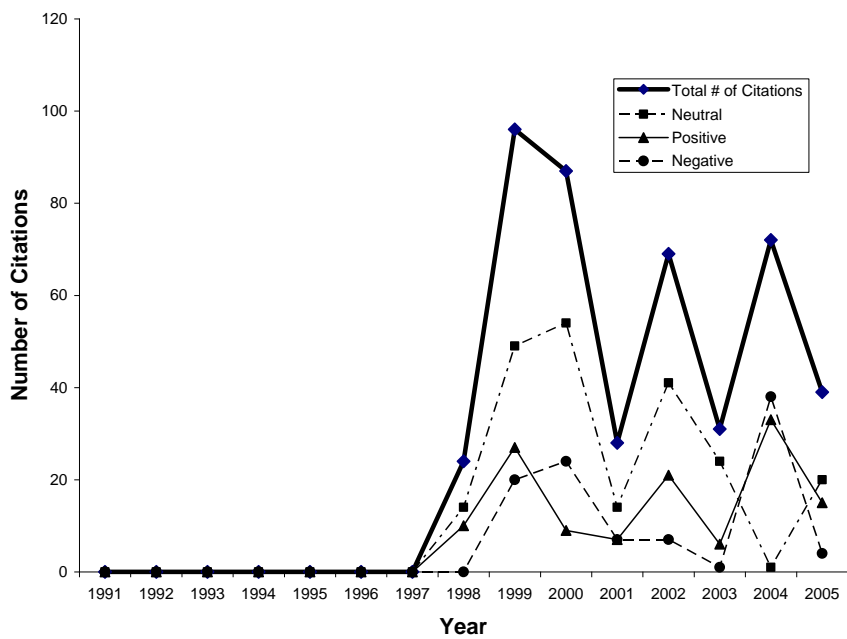
Figures 1 through 8 reflect popular media citations for each treatment during the period from 1991 to 2005. Popular media citations include any reference to the treatment in video, magazine, or news media. The figures show that all controversial treatments initially received mostly favorable publicity, and some have continued to receive favorable reports (e.g., the GfCf diet). Others such as FC, Secretin, and Chelation began receiving negative publicity at about the same time that disconfirmatory research findings or reports of side-effects were reported in the scientific literature. However, FC has recently enjoyed a new wave of favorable publicity.



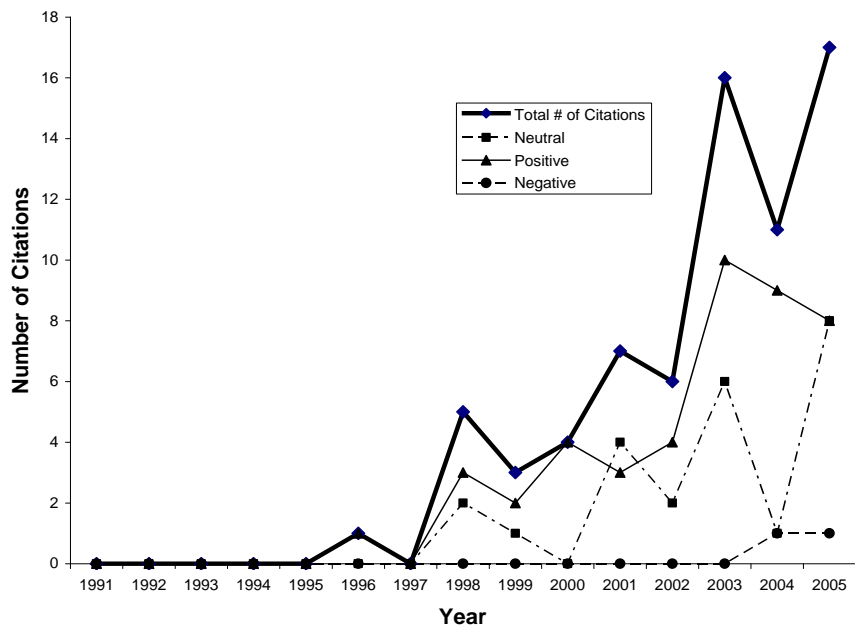
Popular Media Citations for Chelation Therapy 1991-2005



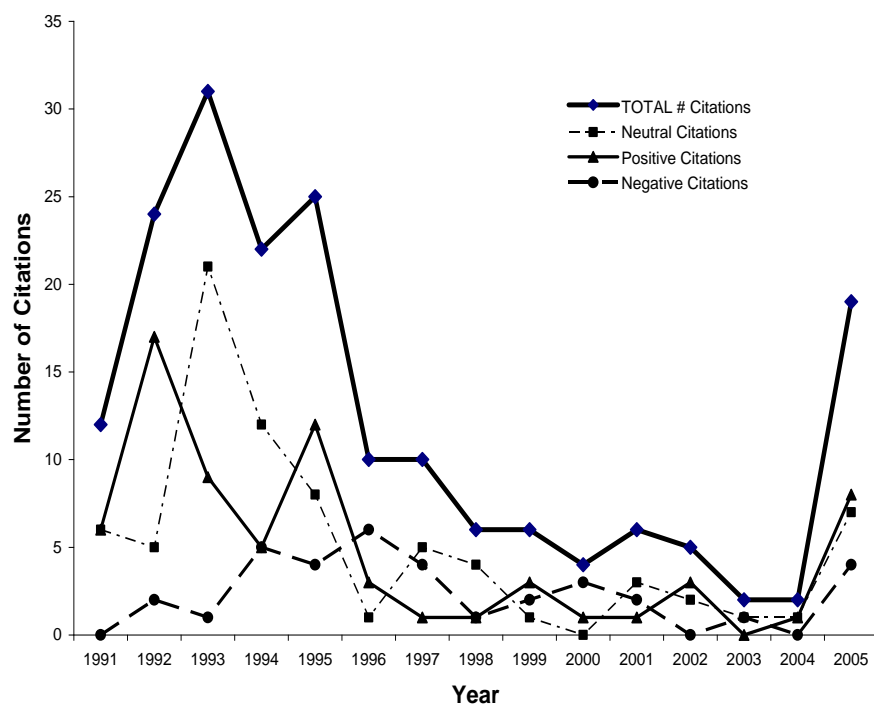
Popular Media Citations for Secretin Therapy

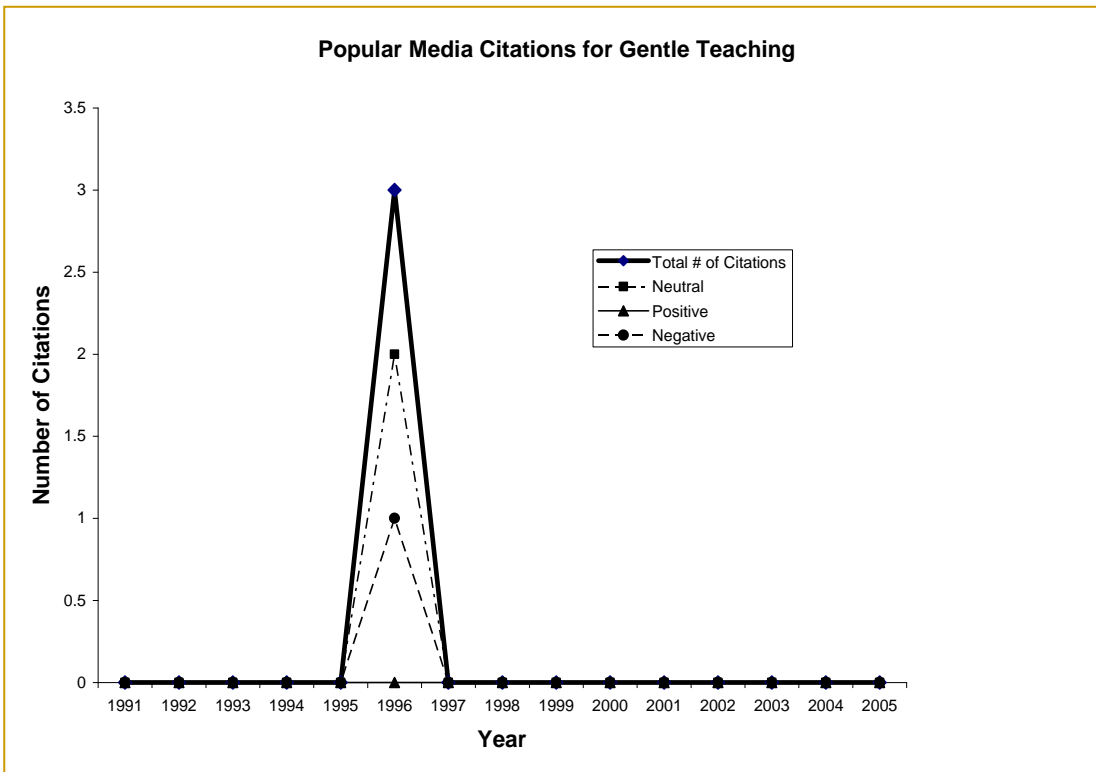
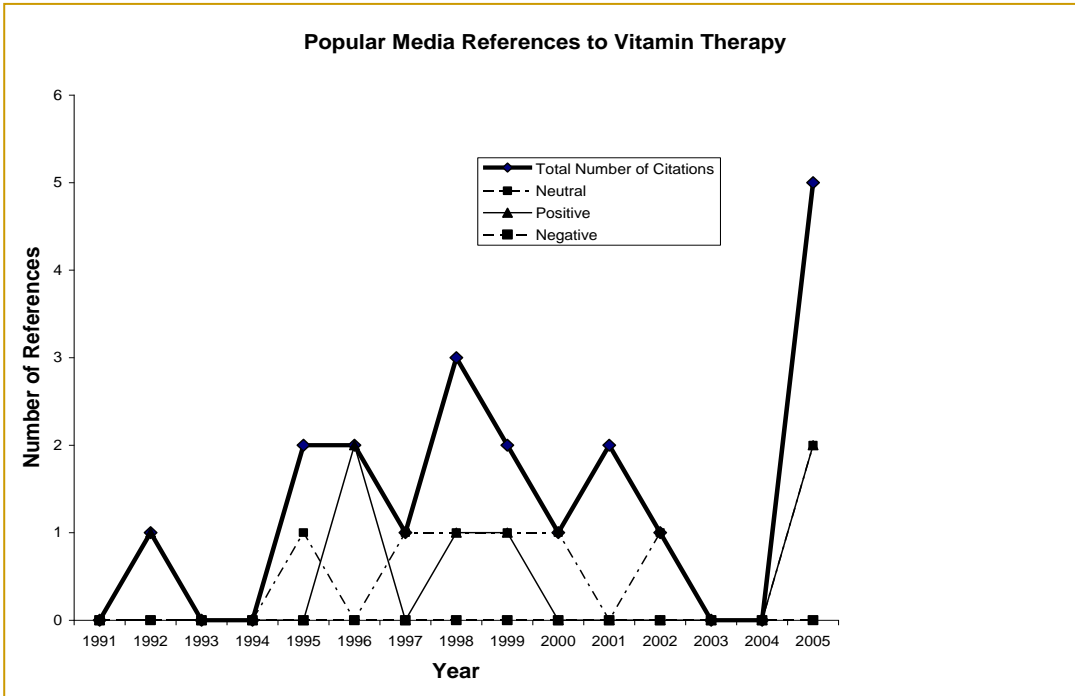


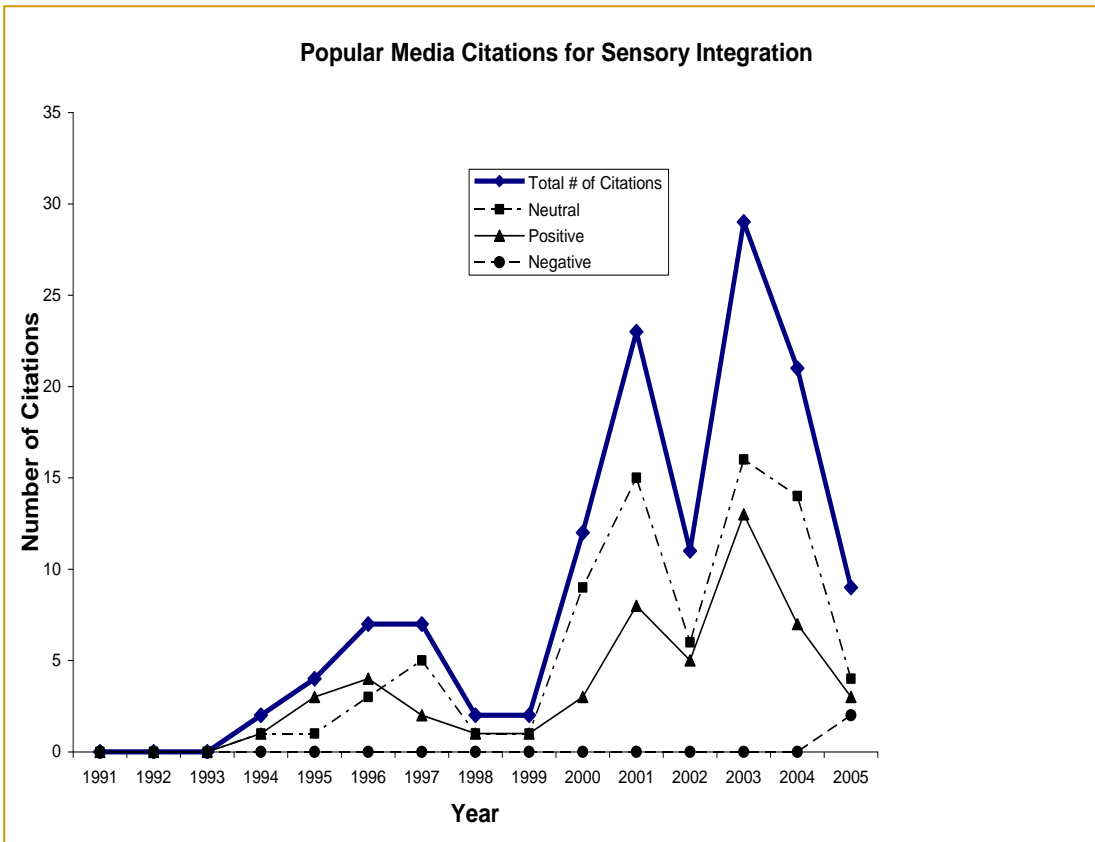
Popular Media Citations for the Gluten-Free Casein-Free Diet



Popular Media Citations of Facilitated Communication 1991-2005







### Discussion

Media reports were mostly positive or neutral and usually cited anecdotal evidence rather than research studies. The number of reports for a given treatment often reflected high-attention anecdotal accounts rather than research findings. Positive reports continued to appear on interventions such as FC and Secretin despite strong evidence indicating that the interventions are not effective. In general, references to controversial treatments increased over time, with a growing focus on biomedical treatments.

Controversial treatments for children with autism attract more media publicity than evidence-based treatments and psychopharmacological therapies. Media portrayal of these treatments emphasizes anecdotal evidence and frequently touts them as cures, despite a clear lack of sound methodological or theoretical studies from within the scientific community. Levy and Hyman (2003) advise that clinicians, researchers, and parents be reasonably aware of current and emerging controversial treatments.

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## Interviews

### **An Interview with Gina Green, Ph.D., BCBA**

David Celiberti, President

Association for Science in Autism Treatment

*As you all know, parents of children with autism are confronted by a dizzying array of treatment options, most of which are not scientifically validated. I recently had the opportunity to interview Dr. Gina Green who has been a tireless advocate for the use of science to guide autism treatment. Dr. Green was gracious enough to share her insights and experiences.*

*Gina Green received a PhD in Psychology (Analysis of Behavior) from Utah State University in 1986 following undergraduate and master's degree studies at Michigan State University. She has been a faculty member in Behavior Analysis and Therapy at Southern Illinois University; Director of Research at the New England Center for Children in Southborough, Massachusetts; Associate Scientist at the E.K. Shriver Center for Mental Retardation in Waltham, Massachusetts; and Research Associate Professor of Psychiatry and Pediatrics, University of Massachusetts Medical School. Dr. Green is currently in private practice in San Diego as a consultant and is on the faculty at San Diego State University and the University of North Texas. She has authored numerous publications on the treatment of individuals with developmental disabilities and brain injuries, as well as the experimental analysis of behavior. Dr. Green co-edited the books *Behavioral Intervention for Young Children with Autism* and *Making a Difference: Behavioral Intervention for Autism*. She serves or has served on the editorial boards of several professional journals in autism, developmental disabilities, and behavior analysis. Dr. Green also serves on the Autism Advisory Group of the Cambridge Center for Behavioral Studies, and the advisory boards of several autism programs and organizations. She is a Board Certified Behavior Analyst, former president of the Association for Behavior Analysis and the California Association for Behavior Analysis, a former member of the Behavior Analyst Certification Board, and a founding Director of the Association of Professional Behavior Analysts. Dr. Green is a Fellow of the American Psychological Association and the Council for Scientific Medicine and Mental Health. *Psychology Today* named her "Mental Health Professional of the Year" in 2000. In 2005 she received an honorary Doctor of Science degree from The Queen's University of Belfast, Northern Ireland for her work in autism. Dr. Green lectures and consults widely on autism and related disorders, behavioral research, and effective interventions for people with disabilities.*

**Please tell us about how you first become involved in raising concerns about pseudo-science, particularly your efforts to challenge proponents of facilitated communication.**

I learned my first lessons about skepticism and scientific reasoning from a wonderful high school psychology and biology teacher. Thanks to him, I was dubious about nonscientific interventions almost from the moment I became interested in autism as a college student. But my first serious encounters with pseudoscience occurred in 1992 when some parents of youngsters at the New England Center for Autism (now the New England Center for Children) asked the Center to use a new technique called Facilitated Communication (FC) with their children. As Director of Research, part of my job was to keep Center staff abreast of relevant research, so right away I checked the scientific research literature for studies on FC. I found nothing, indeed no scientific studies on any aspect of autism by any of the leading proponents of FC. The only article I could find was a promotional description and discussion piece published in a journal edited by Harvard graduate students in education. I checked with colleagues who had been working in autism for many years; none of them had heard of FC or any of its proponents. Fortuitously, I was invited to spend a month that summer as a visiting scholar at a university in Melbourne, Australia where FC originated. While I was there I had lengthy discussions with a number of professionals and family members who had had experience with the technique, and I visited a center run by the leading Australian promoter of FC. Two psychologists who had conducted objective tests of FC authorship generously shared their data, videotapes, and experiences with me. I learned that several well-controlled tests conducted there in Victoria starting in the late 1980s had shown clearly that "facilitators" -- not people with disabilities -- controlled the spelling of messages through FC. Some of the controlled testing had been necessitated by false allegations of sexual abuse that had been produced through FC, with no corroborating objective evidence. I knew that few, if any, people outside of Australia were aware of those data, because they were misrepresented and downplayed in the article mentioned earlier.

By that time FC was already spreading like wildfire throughout North America and elsewhere, hyped by the popular media, Syracuse University, and many people in special education and disability services. The hype was being accepted uncritically; few skeptical voices were raised. So when I returned to the U.S. I started contacting people who were conducting controlled tests of FC authorship, gathering all kinds of information about FC, and giving presentations in which I presented the data from the controlled tests and argued that FC needed to be evaluated scientifically. At the New England Center we decided not to reject FC out of hand, but to conduct our own controlled pilot study. We sent our speech-language pathologists to be "certified" in FC by Douglas Biklen of Syracuse University, and invited the parents who were enthused about FC to participate in the study by serving as facilitators and suggesting methods for testing authorship. Our tests were designed to "stack the deck" in favor of detecting any valid communications by the three young men with autism who participated. We really tried to use FC as it was prescribed by its developers, and to address concerns about other controlled testing that had been raised by proponents. On scores of trials using various techniques to test FC, we found that accurate and coherent messages were spelled when the facilitator was able to see the letter display and knew the expected message. When facilitators looked away from the letter display, random strings of letters were produced. When facilitators clearly did not know the expected message but could see the letter display, lots of words and sentences were spelled, but they were not relevant to the context or accurate answers to questions. Over the ensuing months and years, dozens of well-controlled studies conducted in several different countries got similar results. Yet people were being jailed and families were having their children with disabilities

taken away from them on the basis of "facilitated" allegations of abuse. Thousands of people with disabilities were being deprived of opportunities to communicate for themselves because FC had been adopted by hundreds of schools and service programs. Of all the nonscientific therapies and treatments for autism I had seen to that point, none had caused such widespread harm. So I felt compelled to speak up about those harms and the need for scientific and skeptical evaluation of claims about FC and all other autism interventions.

**It is unfortunate that you and others had to work so hard to study and evaluate this methodology when the onus should be on treatment proponents to provide legitimate data to substantiate their claims. Considering ample data disputing these claims, why do you believe FC keeps re-emerging?**

Like other pseudoscientific therapies and treatments, FC seems to promise a quick and easy solution to a very difficult problem. Those kinds of promises are very hard for many to resist. It also has tremendous emotional appeal for parents, teachers, and therapists who want nothing more than to be able to communicate with their children and students with autism and other disorders. FC has been marketed very effectively to play to those hopes and to a number of fears as well. The mainstream autism culture has always had a strong antiscientific component, so it has long provided a fertile breeding ground for therapies and social movements that are not grounded in science. For those and other reasons, promoters of techniques like FC will probably always find a ready market. It has now been over a decade since many of the controlled studies of FC were published, some nasty legal cases came to light, and FC was exposed as bogus on TV programs like "Frontline" and "60 Minutes." That means that there is now a new generation of parents and teachers who are unaware of the overwhelming evidence that FC is not just ineffective, it's harmful. Sadly, proponents of FC -- who have yet to produce a scintilla of objective evidence to back up their claims -- are not telling the new generation about that evidence, so FC is once again supplanting effective methods of teaching communication skills in many schools and programs.

**What lessons should advocates of scientifically validated treatments learn from the resilience of FC?**

Never underestimate the power of pseudoscience, or how much better it sells than does science. Understand that to use, endorse, or just keep silent about pseudoscience is to collude with pseudoscientists and perpetuate pseudoscientific practices. It's a classic situation where a little reinforcement can be a dangerous thing. It's also a reminder that it's not safe to assume that data alone will suffice to convince people to adopt or abandon a treatment or therapy.

**Clearly those who advocate for scientifically validated treatment are often burdened with responsibilities shirked by those who advocate for pseudoscience. How can this responsibility become more shared?**

I have some hope that the movement toward evidence-based practices will help build support for scientifically validated treatments while also raising awareness of the importance of testing *\*every\** treatment claim scientifically. It's very unfortunate, though perhaps a good thing in the long run, that other pseudoscientific treatments in autism are proving to be very harmful. As

those harms are publicized more widely, perhaps more people will come to value science as a means to prevent those harms. My hope is that someday everyone who works in autism will feel a responsibility to learn the basics of scientific method and critical thinking, and to teach those skills to others.

**You have been at this for many years. How has your approach to challenging pseudoscience evolved over time?**

I think I have a better understanding of the appeal of pseudoscientific treatments to family members than I once did, and I hope I've learned a little about how to communicate that understanding as well as how to communicate scientific concepts to general audiences. One encouraging thing I've observed is that although people often react angrily when first presented with data that contradict their beliefs about a theory or treatment, some eventually come to realize that they've been sold a bill of goods. I've found that a lot of parents are hungry for scientifically sound information about autism, and appreciate it when someone takes the time to walk them through the logic -- or illogic -- of some of the claims about treatments that they've seen on the Web or in books or on TV. So I try to do that, in hopes of giving them tools they can use to evaluate claims for themselves.

**Given the significant impact that pseudoscience has had on our field, what should organizations do to address this issue?**

I would certainly like to see more autism organizations advocating for scientifically validated treatments, and educating their constituents about the dangers of pseudoscience. Behavior analysis organizations could help by offering sessions on critical thinking and pseudoscience at their conferences, and by using scientific standards to select conference speakers and screen conference presentations.

**Those are wonderful recommendations. What are some suggestions you would make to behavior analysts working on multi-disciplinary teams?**

In my opinion, behavior analysts have a professional responsibility to discourage the use of nonscientific therapies and techniques promoted by other professionals -- including fellow behavior analysts. That should be done in a respectful but candid way. I find it helps to preface such comments by saying that as a Board Certified Behavior Analyst, I'm obligated by my profession's code of ethics to use and endorse treatments that have proved most effective in sound scientific studies. I also find it helpful to point to or provide the supporting evidence to emphasize that my position is based on something other than opinion and personal belief. If a member of another discipline asserts that there is scientific support for a technique they want to use on a consumer, I suggest asking them to provide the team with the supporting studies. When feasible, behavior analysts can also offer to help other professionals evaluate the effects of interventions using the methods of our science.

**What are the three most important things needed to attenuate the influence of pseudoscience?**

- Education and training. It would be great if colleges and universities required every student to take at least one course in critical thinking and the basics of scientific method.
- More people of science and reason speaking up about the harms and dangers of pseudoscience, and the wonders and benefits of science.
- Professional organizations, advocacy organizations, and government leaders taking a stand for science and refusing to reinforce pseudoscientific behavior.

**Thank you very much for sharing your experiences with the SIG membership. Your convictions, suggestions, and perspectives are invaluable.**

## **Walking the Line Between Giving Parents Information They Want and Supporting Only Scientifically-Validated Treatments**

An interview with Suzanne Buchanan, Psy.D., BCBA, is the Clinical Director at Autism New Jersey, formerly COSAC. A licensed psychologist, she provides clinical training and direction for staff and is actively involved in advocacy efforts through legislation and various state departments that serve individuals with autism spectrum disorders.

### **What treatments does Autism New Jersey endorse and not endorse?**

Due to the substantial empirical support for Applied Behavior Analysis (ABA) and the related field of Positive Behavior Supports (PBS), Autism New Jersey endorses these two methods. Research on auditory integration training, facilitated communication, and secretin, as well as professional consensus on psychoanalysis, has demonstrated that these methods are ineffective and potentially harmful. The agency does not endorse these methods. The agency cautions consumers to become as informed as possible before administering an alternative treatment to an individual with autism.

### **How do you explain to parents unfamiliar with research the difference between a scientifically-validated treatment and one that is not?**

We explain that some interventions have been tested with individuals with autism and others have not, and how helpful these tests can be. When an intervention is tested, we know so much more about if it works or not, under what conditions it may work for a particular individual, and the possible negative side effects. Untested treatments can be helpful or harmful. We emphasize the importance of data collection on all treatments so that parents and providers can closely monitor the child's behavior before, during, and after the intervention.

It is important for parents to recognize the difference between scientifically-validated treatments and those that are not so that they can decide how to allocate their resources. Being an informed consumer is critical when so many different "treatments" are marketed to the autism community. While some parents may cautiously approach or avoid alternative interventions, others approach them with a sense of optimism. While parents' exploration of alternative treatments is understandable, we encourage them to use accountability measures such as the identification of meaningful outcomes, operational definitions of the target behavior and procedures, and data collection and analysis.

### **How do you support parents who do not have access to scientifically-validated treatments due to prohibitive costs or unavailable services?**

As a nonprofit agency, we are able to provide free parent education classes about ABA principles and techniques. Parents and professionals also can order one free copy of our booklet, *Applied Behavior Analysis and Autism: An Introduction*. We like to think of it as the free guide that tells you which books will offer empirically-validated strategies. With so many titles written for the autism community today, the number of choices can be overwhelming. The resources mentioned in this booklet are a great starting point to learn about ABA in home and educational settings.

Regarding unavailable services, we are working on a few fronts. First, the availability of behavior analysts is a

direct result of the number of graduate training programs. Autism New Jersey actively supports these training programs. Every year we encourage BACB-approved university coursework programs to advertise at our conference, which attracts more than 1,400 attendees. We supported Caldwell College's initiative to establish a doctoral program in ABA.

Second, we funded the printing of the Autism SIG's *Consumer Guidelines for Identifying, Selecting, and Evaluating Behavior Analysts Working with Individuals with Autism Spectrum Disorders*. Agency staff regularly disseminates this publication free of charge to educate both consumers and professionals. Ideally, consumers will become more informed and demand high-quality services from providers and health insurance companies. Also, perhaps professionals will view these criteria as a tool to guide their professional development.

Third, our clinical and public policy staff is working closely with state legislators and government officials to enact a law that would mandate health insurance coverage for ABA services. As of this writing, this proposed legislation has strong bipartisan support and we are diligently working to one day realize our goal of insurance coverage for evidence-based practices for all individuals with autism.

**Given your agency's commitment to evidence-based practices, how do you support parents who are looking for information on alternative treatments?**

We do our best to provide balanced information about how the intervention is proposed to work and the state of research (or lack thereof) on its use with individuals on the spectrum. We also provide them with an article co-authored by David Celiberti, Ph.D., BCBA, on evaluating all intervention methods. We include a lengthy list of questions for parents to ask including, but not limited to, the methodology itself, specific service providers, how their child may or may not be a good candidate for the intervention, and how progress will be measured. This article, *The Road Less Traveled: Charting a Clear Course for Autism Treatment*, is printed in our agency's *Autism: Basic Information* booklet. The first copy is available free of charge.

**Thank you so much for taking the time to talk with me today. Any final thoughts?**

Every day, parents are forced to make some of the hardest decisions of their lives with the hopes of improving their children's quality of life. It is our hope that the afore-mentioned resources, combined with our staff's compassion, make these decisions easier for parents and ultimately improve the quality of service provision for individuals with autism.

## Program Description

### Relationship Development Intervention®: A Review of the Research

Suzanne Letso, M.A., BCBA & Thomas Zane, Ph.D., BCBA

One relatively new treatment approach proposed to treat autism spectrum disorders is Relationship Development Intervention® (RDI®). RDI is an intervention that is identified as a parent-based treatment designed to remediate the "core deficits" of autism spectrum disorders (Gutstein, 2001; 2005). In this context, "core deficits" are hypothesized to be "a failure in developing flexible collaboration of neural sub-systems, competence in dynamic systems, and motivation to master increasingly complex dynamic systems; a desire to both remain in static systems and to amplify the static elements of dynamic systems, and a self-concept based on static competence," (Gutstein, 2004). All other signs and symptoms typically associated with autism spectrum disorders, such as behavioral deficits or excesses, and language deficits (Volkmar, Lord, Bailey, Schultz, & Klin, 2004) are hypothesized to be "co-occurring conditions" (Gutstein, 2001). Additionally, the RDI program was developed specifically to target "deficits in Experience-Sharing in a systematic manner, resembling stages of typical development" (Gutstein, 2006, Unpublished Manuscript, p. 3).

Since its inception, RDI has been widely marketed, but there was no actual research of this methodology reported until September 2004 when Gutstein pre-released a manuscript to the public via his website (Connections Center, 2004). This manuscript was identified as a "*Preliminary Evaluation of the Relationship Development Intervention Program*" and was accepted for publication in the *Journal of Autism and Developmental Disabilities*

(JADD). This report was ultimately slated for journal publication in September 2007 but was later withdrawn by the author in July 2007.

Although never published, this preliminary report has been widely distributed over the last four years. It has been erroneously cited in a second publication (Gutstein, Burgess & Montfort, 2007), is referenced by RDI consultants and proponents of evidence of program efficacy (KidsAhead Consulting), and in marketing materials downloadable from the Connections Center (Connections Center 2005; 2006a; 2006b; Gutstein & Sheely, 2004; Gutstein, 2005). Because this report has been so broadly circulated in the public domain, a review of this report is warranted in spite of its status as an unpublished manuscript.

In this report, Gutstein himself identified 11 factors that negatively impacted the value of his report as evidence of treatment effectiveness. These factors alone make determination regarding a causal relationship between treatment and outcome difficult. However, in addition to the concerns identified by the author, there are a number of other methodological issues not cited by Gutstein that further compromised the scientific significance of this study. The research design was a simple experimental-control group pre-post test design, insufficient for determining a causal relationship between RDI and improvement in subjects. Furthermore, the data collection method was chart review of subjects who had already gone through the RDI program. The RDI group had 5 more months or intervention, or 30% more treatment time than the comparison group, the description of the treatment provided to both the RDI group and the comparison group was insufficient to facilitate replication, the RDI group had a significantly higher percentage of children diagnosed with Asperger's Syndrome and a substantially higher average IQ than the comparison group, which could represent a considerable difference in cognitive ability and the RDI group subjects were an average of one year younger than the subjects in the comparison group.

In spite of these limitations, and subsequent to his withdrawal of the article from JADD, Gutstein published a second paper in the journal *Autism* (Gutstein, Burgess, & Montfort, 2007) in September 2007 citing his preliminary report as "in press in JADD" and summarized its findings as follows:

This study examines the effectiveness of a cognitive-developmental parent-training model, Relationship Development Intervention (RDI) (Gutstein, 2001), and is a follow-up to a preliminary evaluation study (Gutstein, in press, [unpublished manuscript]). In that study, children diagnosed with autism spectrum disorder who participated in RDI demonstrated significant reduction in experience-sharing related symptoms, as measured by the Autism Diagnostic Observation Schedule (ADOS: Lord et al., 2002). Following an average of 16 months of treatment, over 50 percent of children in the study no longer met ADOS criteria of autism spectrum disorders. In contrast, a comparison group of children treated with more traditional intensive intervention methods failed to show significant improvement in these core deficit areas, despite receiving up to five times more therapist involvement than the RDI group. The children in the RDI group were also significantly more likely to function without support in typical classrooms. (p. 398).

Not only does this second paper fail to note any of the 11 limitations identified by the author and incorrectly identify the report as already published, this second study also does not meet established research standards. For example, Gutstein once again took his data from a review of existing charts of children who had been involved with RDI treatment over varying lengths of time. Thus, there was no direct observation of behavior, and no opportunity for establishing dependent measure reliability. Gutstein used what would be considered an "AB" design without a control group. The confidence of cause and effect being established with this type of design is quite low. Furthermore, there was no definition of key terms, no detailed description of the treatment strategies, and no check on treatment fidelity.

And, similar to the first study, this second study does not demonstrate a clear relationship between the independent and dependent variables. Gutstein identified a number of limiting factors such as data collected solely from chart reviews, the assessment was restricted to families treated at The Connection Center rather than through an RDI consultant, exclusion of children who were older than 9 years of age at the outset of treatment, and exclusion of children with more severe cognitive difficulties, i.e., an IQ range of 70 – 188, with a mean IQ of 90.5 (Gutstein, et al., 2007). In addition to these considerations, ADOS scores were presented for only 12 of the 16 students reviewed, and only selected items from both the ADOS, ADI-R were utilized to assess progress rather than the tests in their entirety. In addition to participating in the RDI program, at least 14 of the 16 students were placed in other school programs, and a percentage of students also received behavioral treatments and/or biomedical interventions, which makes it impossible to attribute results solely to the students participation in the RDI program.

Even if either of these two studies had produced compelling evidence in support of RDI as it was implemented in the years 2000 – 2005, RDI has undergone "major revision of all the child objectives, starting from the ground up, covering all major domains of the deficits of Autism Spectrum Disorders, and including: foundations, discover-

ies, elaborations and mastery criteria for each. Over 1,000 objectives in total,” (Connections Center, 2007). This mercurial evolution renders the results of those two studies irrelevant in relation to current practices.

In summary, there have been two assessments disseminated by the developers of the RDI program. Neither study meets basic criteria to be considered compelling evidence of program efficacy. To date, there are no peer reviewed research articles supporting the utilization of RDI programs for learners with autism or any other disability.

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## Article Synopses

We had originally planned on having a synopsis of the article by Howard, Sparkman, Cohen, Green, & Stanislaw (2005), *A comparison of intensive behavior analytic and eclectic treatments for young children with autism* in this issue of the newsletter, because of its relevance to a discussion of important and effective treatment approaches. This study examined the impact of intensive behavior analytic intervention compared to either intensive eclectic intervention or less intensive generic special education on young learners with autism.

The results of the study showed very clearly that intensive ABA intervention produced significant gains in all areas of functioning, compared to either of the other two groups. The authors concluded that eclectic intervention was ineffective, even when applied in a highly individualized and intensive way. This study is extremely important in highlighting the importance of an intensive intervention program that is thoroughly behavior analytic. Given the extent of generic or mixed-method programs, it is imperative to share this information with consumers.

We have opted not to have a more in-depth review of the paper and its implications, because an outstanding article by Jane Howard and Gina Green, two of the authors of this study, was just published in the APBA (Association of Professional Behavior Analysts) newsletter. Please read it, and disseminate it to the families and school personnel that you work with. (APBA is the newly formed organization designed to meet practitioner needs. Please check out their website [www.apbahome.net](http://www.apbahome.net).) The article can be located at <http://www.apbahome.net/newsletter.php?nid=1&aid=5>.

***The Complete Guide to Autism Treatments  
A Parent's Handbook: Make Sure Your Child Gets What Works***

S. K. Freeman, Ph.D.  
ISBN# 978-0-9657565-5-6

Reviewed by David Celiberti, Ph.D., BCBA  
President, Association for Science in Autism Treatment

Dr. Freeman is a prolific writer who has published numerous works related to autism and its treatment. Her latest book, *The Complete Guide to Autism Treatments*, may indeed be her most important contribution to parents of children with autism, as well as to those professionals who work with this clinical population. The book is comprehensive, thoroughly researched, and well organized. Throughout the book, Dr. Freeman communicates a critically important message: Individuals with autism deserve access to science-based treatment; their time, their potential, and the overall resources of their families should never be wasted. The Board of the Association for Science in Autism Treatment ([www.asatonline.org](http://www.asatonline.org)) could not agree more.

The book is divided into two primary sections. Section I is organized around topics related to the various treatments for autism, of which there are several dozen. Section II highlights basic concepts about science, hypothesis testing, and research methodology. Section I begins with a review of behavior-analytic treatments for autism across home and school settings, as well as within the area of early intervention. The various offshoots of applied behavior analysis are also summarized and evaluated. Then there is a fairly comprehensive section related to the myriad non-behavioral treatments, including those that occur in school, as well as those that are child-initiated or parent-facilitated. These subsections are followed by biomedical therapies, speech and language therapies, and, ultimately, a final section for miscellaneous therapies not better categorized in the above subsections. Each of these subsections is divided, and in some cases divided further, in an effort to capture the more frequently-touted treatments for autism.

It is frankly unfortunate that such an extensive taxonomy is needed simply to categorize all that which is available to consumers, particularly given that the vast majority of treatments proposed for autism lack adequate scientific support. Consumer advocates who think that exposure to many diverse treatment options is a good thing are likely not considering the agonizing decisions parents must make about how best to help their child with autism, the second guessing and guilt that may come from worrying that one is not doing enough, and the extraordinary financial

burdens that come from paying for numerous treatments out of pocket.

Parents of children with autism - particularly those with newly diagnosed children - face a dizzying array of options that can be absolutely overwhelming. Do parents of children from any other clinical population have to face these matters to the extent that we see in autism? Quite simply, no. Parents of children with autism deserve all of the information needed to consider possible treatments carefully and to make the most informed decision for their child. Fortunately, this book will be of tremendous help in that regard, for Dr. Freeman's review and description of the available research is presented in a careful, thorough and straightforward manner. Each of these treatment subsections is organized around responses to a series of 9 questions.

**“What is \_\_\_\_?”**- Here, D. Freeman defines the treatment and describes its rationale and theoretical underpinnings.

**“What evidence do the practitioners have that this really works?”** – The author summarizes and evaluates peer-reviewed research and other possible sources of support.

**“What does this therapy actually look like?”** - Dr. Freeman describes, often in great detail, the actual procedures associated with the treatment. These descriptions are written in an objective, non-partial manner which, when read in isolation, would not necessarily reveal the author's stance on a particular treatment.

**“What else do I think?”** - Dr. Freeman speaks to broader issues that bear relevance when judging the merits of the particular intervention. She reveals her impressions of the treatment in a very forthright and compelling manner.

**“Would I try it on my child?”** - In contrast to the objective and factual tone of her responses to the questions above, here Dr. Freeman offers a more personal take on the treatment, a take that is honest and at times blunt. Clearly, every child with autism is different, and, thus, treatment decisions need to be made in consideration of those differences. Even if readers disagree with Dr. Freeman's stance, they will appreciate the candor and thoughtfulness of her position as a fellow parent.

**“What kind of study would I like researchers to do?”** - Perhaps the most insightful arguments can be found in these responses. Dr. Freeman argues that it is not sufficient that treatment proponents simply churn out publishable research, but rather that they design research that carefully addresses questions pertinent to that particular treatment. These may include, but not be limited to, better definition of the independent variable, use of tighter research designs, selection of more appropriate dependent variables, and a clearer demonstration of the relationship between the manipulation of the independent variable and the dependent variables. These particular sections clearly demonstrate Dr. Freeman's command of the existing research and what is needed to move forward.

**“Who else recommends for or against \_\_\_\_ as a method for the treatment of autism?”** – Dr. Freeman highlights recommendations from professional-membership organizations such as the American Academy of Pediatrics and the American Speech-Language-Hearing Association, from state and federal government entities, and from other organizations such as Quackwatch. It is important to point out that position papers from organizations represent a consensus among leading scientists and clinicians based on a thorough review of evidence and experience. These recommendations should be an important factor in decision making and I applaud Dr. Freeman for reporting them throughout her book.

**“So you're still on the horns of a dilemma?”** - Dr. Freeman provides further information for those still struggling with their decision for any number of reasons.

And finally, **“What's the bottom line?”** is written for those seeking a concise thumbs up/thumbs down assessment.

Section II, as mentioned, focuses on science, hypothesis testing, and research methodology. At times, the content may seem somewhat dense but that speaks more to the complex nature of scientific inquiry than to Dr. Freeman's writing style per se. These more technical sections are preceded by a number of caveats empowering parents to question the “experts” whom they will undoubtedly encounter over the course of their child's treatment. Section II ends with a description of all-too-common red flags in autism treatment.

This book has many notable strengths. The format of 9 recurring questions within Section I provides a predictable framework for the reader. In fact, Dr. Freeman's careful analysis of the state of the research underlying specific ABA treatments is offered in the same spirit and with the same diligence as the non-behavior analytic treatments. This is critically important, given that the abundance of research in ABA may mistakenly give the impression that

all that falls under the umbrella of ABA is well supported empirically. This could not be further from the truth. Although some behavior analysts who are proponents of Positive Behavior Support, Verbal Behavior Therapy, Fluency Training, and Pivotal Response Training may disagree with many of Dr. Freeman's specific assertions, the quality of her analyses and the clarity of her concerns contribute to a much less divisive dialogue than we have seen in other books to date.

Proponents of the various treatments would benefit from careful consideration of the suggestions offered in the "research needed" section. Far too often, a single study is put forth as validation of an entire treatment and all of its theoretical and conceptual underpinnings. For instance, as Dr. Freeman discusses in her book, a published research study that uses an art activity to integrate children with autism with their typically developing peers in no way validates art therapy as a treatment for autism. A well designed study in which a clearly developed treatment protocol for art therapy is implemented and dependent variables are selected that measure core manifestations of autism is the type of research that is desperately needed. The reader will find that Dr. Freeman has individualized her recommendations based on each treatment's existing research history. Execution of these research agendas may enable a number of treatments to live up to their promise.

Perhaps of greatest significance is that the author is writing from the dual perspectives of professional and parent. When speaking as a parent, her commitment to science is unwavering and, appropriately so, she is unapologetic in honestly sharing her perspectives as an informed mother. This is sorely needed at a time when many individuals fear being perceived as close-minded or unwilling to recognize the contributions of other disciplines. Her professional perspective only adds further credence to her stance regarding treatment options.

There are wonderful insights throughout the book which will make this resource useful to those who will tend to read this book a few sections at a time. For instance, there is a very interesting discussion at the beginning of the book about participation in research with the caveat that precious time and resources should never be wasted on low-quality research, for not all research is created equally.

There are a few minor concerns. Many readers may have benefitted from an introduction to some of the content in Section II at the very beginning of the book. To her credit, Dr. Freeman makes the suggestion to review this content first. I suspect this introduction would have laid a foundation for readers to synthesize the tremendous amount of information in Section I. Organizationally, I believe that the judicious use of tables and charts would have facilitated comparisons across treatments. Clearly, many parents are surrounded by those who support their informed decision making and their commitment to science-based treatment. Unfortunately, there are many parents who find their efforts punished or derailed by those with competing agendas. Therefore, this comprehensive resource would have been further strengthened by specific and concrete strategies for both managing the behavior of others involved in treatment decisions, and for resisting and responding to pressures exerted by others to "just try" a particular treatment (e.g., the mother-in-law who argues that the gluten free diet is harmless, so why would one not want to try it).

In summary, I believe this book is a much needed contribution to the field of autism. The diligence and comprehensiveness of the various treatment reviews make this book an important "go-to" resource for parents and professionals alike. Undoubtedly this is a resource that the reader can expect to pick up time and time again.

Gutstein, S. E., Burgress, A. F., Montfort, K. (2007) Evaluation of the relationship development intervention program. *Autism, 11(5)*, 397-411.

Nathan M Lambright, Douglass Developmental Disabilities Center

Autism is a heterogeneous disorder that involves certain universally present characteristics. Experience sharing and flexible adaptive thinking are two such characteristics that discriminate between affected and non-affected samples. Relationship Development Intervention (RDI) is a treatment for autism spectrum disorders that utilizes a cognitive-developmental parent-training model to target these ubiquitous symptoms.

RDI utilizes parents as the primary agents of change, in addressing children's perceptual, cognitive, and emotional difficulties. Parents attend 6 days of intensive workshops to learn the RDI skill set, followed by regular weekly or biweekly consultation meetings with a certified RDI consultant. These meetings utilize progress updates, and the review of videotaped segments of caregivers working with their children, to aid in program planning

and the discussion and creations of goals. For a more thorough overview of the procedures involved in Relationship Development Intervention see *Relationship Development Intervention with Young Children: Social and Emotional Development Activities for Asperger's Syndrome, Autism, PDD, and NLD* (Gutstein & Sheely 2002).

A preliminary study found RDI to be an effective intervention for autism. In that study, children had a significant reduction in experience-sharing related symptoms, both immediately after treatment, and at a 16 month follow-up. In addition, over 50% of subjects no longer met ADOS criteria for an autism spectrum disorder. The control group, getting a traditional treatment, both showed poorer results and received five times more therapist involvement than RDI. The current authors attempted to test the durability of these changes with more extensive follow-up procedures.

## **Subjects**

Sixteen children, ages 21-94 months were included in this study. Subjects were required to have a diagnosis of autism, Asperger's syndrome, or PDD-NOS prior to treatment; have participated in the RDI protocol; have a pre-treatment IQ of at least 70; and had an interval of at least 30 months between initial and follow-up testing. The subjects were primarily male (15-1), five had diagnoses of autism, seven had diagnoses of Asperger's syndrome, and four had diagnoses of PDD-NOS.

## **Measures**

Subjects were assessed using five measures. The Autism Diagnosis Observation Schedule (ADOS) is the gold standard diagnostic assessment for autism spectrum disorders. It is highly stable and relatively unaffected by age or time. The measure gives four subscale scores and a summary diagnostic rating placing the subject in the category of autism, autism spectrum, or non-autism. The Autism Diagnostic Interview-Revised (ADI-R) is a diagnostic interview for autism which was developed to supplement the ADOS. It examines 'qualitative abnormalities in reciprocal social interaction', 'qualitative abnormalities in communication', and 'restrictive and stereotyped patterns of behavior' both in the past and at the time of the interview. Thirteen items were isolated in the ADOS and ADI-R as a fourth measure to measure experience sharing. A semi-structured parent interview developed by the authors to measure flexibility was the fourth measure. This interview consisted of 10 items related to the child's ability to adapt to change and transition. Educational placement was used as a fifth measure and determined by parent interview. The ADOS and ADI-R are vigorously studied measures which have been validated by numerous studies while the flexibility interview is a currently untested measure.

## **Results**

Prior to treatment ten children met ADOS criteria for an autism diagnosis. After a median of 41.5 months of treatment, no child met criteria for an autism diagnosis; however, five children scored as autistic met criteria for a "non-autism" diagnosis. In addition, an ANOVA of the follow-up results showed that initial improvements made in the first year of treatment were maintained over time. An analysis of social interaction showed a significant time effect, suggesting subjects continued to make significant improvements in social interaction. Examinations of ADI-R scores for communication and social interaction showed a significant and dramatic difference between pre-treatment and follow-up scores; however, results for the restricted and repetitive behavior domain were not reported. Analyses of the ADI-R and ADOS items for experience sharing indicated dramatic improvement in observed functioning, which was consistent with parent ratings. The measure for flexibility also evinced improvements. The average percentage of age appropriate flexibility ratings increased from 16% to 71% from pre-treatment to follow-up. Finally, the data for educational placement showed dramatic shifts in classroom setting. At pre-treatment, more than half of the subjects were placed in special education classrooms while at follow-up, 10 of the sixteen subjects were placed in some level of mainstream classroom. Data for IQ, previous and concurrent psychosocial treatment, and previous and concurrent biomedical treatment were also examined. None of these factor yielded significant relationships with improvements.

## **Discussion**

"Children who participated in RDI became significantly more socially related, engaged in more reciprocal communication, functioned in school settings with less adult participation, and also were perceived by parents as

behaving in a dramatically more flexible and adaptive manner.” The current study builds on initial findings by demonstrating consistent improvements across measurable domains; including observational (ADOS), objective (school placement), and parental perception (ADI-R and flexibility scales). It also shows that these dramatic gains in functioning remained stable during average follow-up periods of three years. Furthermore, the study identified and controlled for the effect of potential confounds that may have been responsible for the improvements seen in the study. Limitations include the lack of a control group, inclusion of only relatively high functioning subjects (as judged by IQ scores that only fell as low as 70 and in some cases reached as high as 118), the restricted age range of subjects that only reached as high as 9 years old at the initiation of treatment, and the self selection of what are conceivably highly committed parents who sought out treatment at the primary training and development site for RDI.

Solomon, R., Necheles, J., Ferch, C., & Bruckman, D. (2007). Pilot study of a parent training program for young children with autism: The PLAY project home consultation program. *Autism, 11*, 205.

#### Amy Hansford, Douglass Developmental Disabilities Center

Extensive bodies of research have emphasized the importance of early, comprehensive and intensive interventions to effectively improve the functioning of children with an autism spectrum disorder. The National Research Council recommends a minimum of 25 hours of intensive intervention per week. When delivered by a professional, these services often range in cost from \$25,000 to \$60,000 a year. For families and school systems alike, the financial and time commitments implicated in successful therapies place a strain on available resources, particularly as prevalence rates continue to rise. This article asserts that “until more developed, institutionalized services are available, a staged approach to intervention using parents as first interventionists has been recognized as the most practical way to deliver initial services.”

Traditionally, two different types of intensive therapeutic interventions have been available to families. Lovaas piloted the behavioral approach, utilizing discrete trial instruction to increase desirable behaviors while decreasing stereotypic behaviors within a classical conditioning framework. While significant gains may be made in increasing the targeted behaviors, the behavioral method is often criticized due to the poor generalizability of these new gains to the natural environment and lack of social interaction with peers. Conversely, the social pragmatic approach created by Greenspan is a “developmental, individualized, and relationship-oriented (DIR) model” which aims to improve communication and socialization while lowering the rates of stereotypic behaviors. While several social pragmatic programs are in clinical use, the scientific research supporting their efficacy is scarce, as these programs are more difficult to quantify than the traditional behavioral methods.

This article outlines a program evaluation for the PLAY (Play and Language for Autistic Youngsters) Project Home Consulting Programs, “which is designed to provide an intensive, cost effective, structured intervention that addresses the language, social and behavioral deficits of children with ASD.” The PLAY project is based on the theoretical framework of the DIR model. To date, there is little research on parents as interventionists, yet the existing studies are encouraging and have shown significant gains made by parent trained children. The PLAY project draws on the fact the parents have the ability to learn to effectively interact with their children to deliver interventions in the home. In Michigan the PLAY Project is a well established autism training and early intervention center. Nationally, up to 50 agencies in 17 states are currently utilizing the model in some form. Additionally, the article is the first to report on well operationalized outcomes based on the DIR model.

#### Method

All 68 participants were between the ages of 18 months and 6 years and were referred to the University of Michigan Developmental and Behavioral Pediatrics Clinic. The sample includes diagnosis of autistic disorder, PDD-NOS, and Asperger's Syndrome. Before implementation, parents were administered a training manual and attended a one day workshop to understand the intervention approach and the importance of engaging with the child reciprocally for at least 15 hours a week. For enrolled participants, home consultants made monthly, half day visits to educate parents on providing comprehensive social pragmatic intervention. In a detailed seven step sequence, parents are taught how to understand the principles of the intervention as it applies to their child's strengths and weaknesses and how to refine the treatment based on observation to increase reciprocal social interaction. Home consultants relied on modeling, coaching, video assessment, and written objectives to help guide treatment and offer feedback throughout the course of the year long study. Average cost per year to implement these programs ranged between \$2500 to \$3000 per family, well below the yearly expense of a private profes-

sional.

To track developmental change before and after the intervention, the Functional Emotional Assessment Scale (FEAS) ratings were used as the primary measure of overall progress. The FEAS is divided into two sections for both the caregiver and child. Six subtests directly reflect Greenspan's six functional developmental levels (e.g., self regulation, representational capacity). Additionally, home consultants rated each child's clinical progress on a related six point scale. Parents were responsible for recording the hours spent in daily logs, and were asked to complete satisfaction surveys at 3 and 12 months.

## **Results**

Using the FEAS ratings, researchers determined that 45.5 percent of children made good to very good functional development gains. Parental scores remained stable when comparing their FEAS scores before and after the intervention. Unsurprisingly, a correlation was noted between lower outcome scores and fewer hours of intervention administered a week. Though the home-based intervention required much effort and dedication on the behalf of the parents, 70% of families reported they were 'very satisfied' with the PLAY project. The chief complaint among those who rated as 'somewhat satisfied' was that the project did not provide enough services.

## **Discussion**

This study showed that a large majority of parents were capable of learning to understand and effectively implement a cost effective intervention strategy. The sample was largely composed of middle to upper class educated families, and these individuals were self selected for the study and likely highly motivated to incorporate a parent training model. Additionally, many families had one parent who was not working and available to dedicate time to the PLAY project.

Within the sample, there was an equal representation of all levels of severity on the spectrum. Historically, children with greater severity are expected to have poorer outcomes. The authors point out the difficulty in predicting which children will do well at such a young age, but that the child outcomes of nearly half of the participants making good developmental gains may not be accounted for by selecting for a sample of only high-functioning children with autism.

Some limitations of the study include the lack of a control group and the finding that the fewer the hours the parents spent with the child, the poorer the outcome. This may suggest that "the parents' time of involvement may be more important than the specific effects of the training program." Finally, near all children enrolled in the PLAY project were also enrolled in an early intervention or special education preschool program. According to the authors, this likely does not confound results, as the total number of hours spent in one-on-one therapy in these interventions is very limited.

Overall, the PLAY project Home Consultation program provides an encouraging avenue for cost-effective, family based intervention. While new cases of autism are being diagnosed every day and the costs of professional interventions continue to rise, more research is needed to investigate the developmental and financial possibilities for these treatment strategies.

## **REMEMBER:**

THE ABAI AUTISM Conference is scheduled in February in Jacksonville, Florida, from February 6th through 8th. There is a wonderful line-up of speakers for this years conference. The title of the conference is "Research to practice: Making real changes in the lives of people with autism." Please visit the ABAI website to see all details. We hope to see many of you there!

## Letter from the ABAI Autism SIG President

Hello! Hopefully the school year is off to a great start. The Autism SIG has been busy working on a number of initiatives including the newsletter, the [www.autismsig.org](http://www.autismsig.org) and [www.pppsig.org](http://www.pppsig.org) websites, as well as ongoing conference planning. As you know, Lori Bechner has assumed her role as President Elect and I am looking forward to working with her closely over the next two years.

Prior to discussing this issue of the newsletter, I would like to address the membership regarding some of our recent activities. We are pleased to announce that at the upcoming ABAI conference in Jacksonville, FL, time will be allotted for Mary Jane Weiss, of the Autism SIG, and David Celiberti, of the PPP SIG to address the importance of special interest groups (SIGs). This will be a wonderful opportunity to highlight the SIG's objectives and how our groups can help educators, parents, and clinicians. The conference, *Research to Practice: Making Real Changes in the Lives of People with Autism*, is being held from February 6-8, 2009, and will have panels highlighting the following themes: "Recent Developments in Behavioral Programming & Interventions" and "Using Science to Guide Autism Treatment."

The Autism SIG and PPP SIG will have tables at the poster session to promote our committees and recruit new members. The PPP SIG is continually trying to reach out to parent attendees at the conferences in order to orient them to the conference and to provide them with relevant information. They are currently working with ABAI to develop ways to reach parent attendees before coming to a conference. The Autism SIG will be supporting the PPP SIG to provide consumer friendly information for this conference as well as in Phoenix.

In preparation for the 35<sup>th</sup> Annual Conference in Phoenix, AZ, May 2009, we are planning to have a table at the EXPO, which was a great success this past May. We have also been preparing for our annual business meeting. After our business agenda, we plan to have a series of very brief presentations ("Show and Tell"). Preselected SIG members will have three minutes to describe and/or show a simple, innovative teaching program, technology, a unique form, chart, data collection tool, or something to improve community awareness. The goal is to provide SIG members with ideas and strategies they can easily implement. If you are interested in submitting your idea, contact Suzannah Ferraioli at [autismsig@gmail.com](mailto:autismsig@gmail.com).

Extensive support and teamwork is often needed to support families who have children with autism and the professionals who work with them. In continuing our commitment to working collaboratively with others in the behavior analytic field, we will be following the lead of several state organizations who have become affiliates of APBA. The Association for Professional Behavior Analysis (APBA) is an organization that plans to address national and state-level issues including licensure, insurance reimbursement, ethical issues, professional networking, and best clinical practices.

There is a growing need for more information and programs supporting adolescents and adults whether in college, a vocational placement, supported work or living programs, or living independently with the skills needed to be successful in life. This issue of the Autism SIG newsletter addresses issues related to preparing for adulthood, beginning with the transition planning process (11-14 years old) into adulthood. Transition planning is mandated by law but many schools and parents need more information in order to develop a comprehensive IEP. A timeline was created to help guide parents and educators when to begin planning and what steps to take at various ages in the student's development. Issues related to advocacy, volunteer programs, and group home models are also highlights in this newsletter edition.

Special thanks to each of our newsletter contributors. The Autism SIG expresses great gratitude to Rutgers for hosting our group all these years and to EPIC, who recently hosted our committee as well.

Enjoy!

Sincerely,  
Ruth Donlin  
President of the Autism Special Interest Group

# RUTGERS

Douglass Developmental  
Disabilities Center

*Please send your suggestions of topic ideas for possible inclusion in an upcoming issue of the SIG newsletter to:*

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