

SCIENCE IN AUTISM TREATMENT

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THE NEWSLETTER OF THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

ASAT SUPPORTS PROVEN TREATMENTS AND INFORMED CHOICE

In an editorial in *Autism Research Review International* (Vol. 13, No. 3, 1999) entitled "The ABA Controversy," Dr. Bernard Rimland described the literature and positions of the Association for Science in Autism Treatment (ASAT) as "nonsensical...counterfactual... indefensible...distorted." He included ASAT among a group he characterized as the "ABA [applied behavior analysis] is the only way folks." Dr. Rimland also spent a fair amount of space reviewing the history of what he represented as his personal support for ABA. In response, ASAT would like to acknowledge Dr. Rimland's contributions to the autism field, and then focus on the real issues here—the health and welfare of people with autism, and the quality of the evidence about autism treatments—rather than anyone's personal history, or opinions, or support for one treatment approach or another.

Without question, Dr. Rimland had a heroic moment in the 1960s when he challenged the self-assured pronouncements of the psychodynamic, "refrigerator mother" camp about the cause and treatment of autism. He deserves a place in the annals of autism advocacy as someone who

was courageous enough to challenge powerful myths and self-proclaimed authorities, and who compiled the then-emergent evidence that autism is a disorder of brain development that is not caused by bad parenting.

But a review of the past few years of *Autism Research Review International* (ARRI) reveals a consistent pattern of premature and uncritical promotion of treatment "breakthroughs" in the absence of credible research support. A number of scientific reviewers have concluded that many of those treatments have proved ineffective or harmful. The research that appears to support several other treatments is methodologically weak, and still others have yet to be evaluated carefully. These include anti-fungal treatments, auditory integration training, dimethylglycine, dolphin therapy, drum therapy ("Rhythmic Entrainment Intervention"), facilitated communication, gluten-and casein-free diets, holding therapy, intravenous gamma globulin, secretin, sensory integration therapy, and vitamin megadoses. Two recent and thorough multidisciplinary reviews found that those treatments are far from being "breakthroughs," or even helpful adjunct treatments for autism, as

they have been portrayed in ARRI (see *NY, Maine Issue Evidence-Based Assessments of Autism Interventions* in this issue of *Science in Autism Treatment*, Vol. 1, Fall, 1999). Consider just a few examples:

Facilitated Communication (FC) was initially given positive coverage in ARRI, which helped spur its widespread, uncritical adoption. Data from numerous controlled studies showing that people with disabilities were not the ones communicating through FC, and reports of families destroyed by false allegations made through FC, were eventually reported in ARRI. By that time, however, hundreds of thousands of taxpayer dollars and uncounted hours had been spent on FC instead of on safe, effective, validated methods for teaching people with autism to communicate for themselves. Based on their own reviews of the scientific evidence, several reputable organizations issued position statements to the effect that FC has no validity or reliability. The first was The American Academy of Child and Adolescent Psychiatry, which stated in 1993 that "Studies have repeatedly demonstrated that FC is not a scientifically valid technique for individuals with autism or mental

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EDITORIAL:

Dear Colleague,

ASAT would like to share our science-based resources with everyone who wants them, free of charge. But to do that, we need your financial help as quickly as possible. As we fight for our children's futures, we have learned that educational outreach based upon accurate, scientifically-sound information is one of our best advocacy weapons. Accurately informed educators, pediatricians, psychologists, hearing officers, attorneys, legislators and policy-makers can have a direct, positive impact on our children's quality of care and education.

A single print run of this newsletter costs thousands of dollars. ASAT is entirely donor supported. If you like what you see in these pages, please send your generous, tax deductible contribution so that ASAT can continue to disseminate accurate, science-based information, and promote access to effective autism treatment. Just fill out the attached coupon and mail it today.

Thank you!

— Lora Perry, Managing Editor

"It is science that guides us, but love that inspires us, and we will not fail our children."

— Catherine Maurice

ASAT MISSION STATEMENT

To disseminate accurate, scientifically sound information about autism and treatments for autism.

To improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income, or place of residence.

WE WILL FULFILL OUR MISSION BY

- Educating professionals and the public about state-of-the-art, valid treatments for people with autism
- Supporting certification, to ensure all individuals with autism receive treatment from practitioners who have met minimum standards of competency
- Forming interactive, supportive partnerships with universities to develop accredited educational programs for autism practitioners
- Improving standards of care for people with autism

VALUES STATEMENT

ASAT is committed to science as the most objective, time-tested and reliable approach to discerning between safe, effective autism treatments, and those that are harmful or ineffective. ASAT supports all scientifically sound research on the prevention, treatment and cure of autism, as well as all treatments for autism that are shown to be effective through solid scientific research, regardless of discipline or domain.

retardation." This was followed by comparable statements by The American Psychological Association (1994), The American Speech-Language-Hearing Association (1994), The American Association on Mental Retardation (1994), The Association for Behavior Analysis (1995), and The American Academy of Pediatrics (1998). At least 40 controlled studies and numerous legal proceedings have now demonstrated that FC is invalid, unreliable, and harmful; no methodologically-sound studies have produced compelling evidence that it is effective. This led the New York State Department of Health (NYSDOH) review panel to conclude, "Because of the lack of evidence for efficacy and possible serious harm of using facilitated communication, it is strongly recommended that facilitated communication not be used as

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an intervention method in young children with autism." (New York State Department of Health, 1999).

Auditory integration training (AIT) has been strongly endorsed in the pages of ARRI over the past several years. In contrast, The American Academy of Audiology (1993) and The American Speech-Language-Hearing Association (1994) issued a policy statement and technical report, respectively, to the effect that AIT lacked scientific validity and had potential negative side effects, including hearing loss. In August 1998, the American Academy of Pediatrics declared that "...as yet there are no good controlled studies to support its use," and further noted that, "Although AIT practitioners declare the technique to be safe, there is some information about both the quality control characteristics of the equipment used and

potentially unsafe sound levels produced by it." The NYSDOH panel found that only one of 16 published articles on AIT with children with autism met established criteria for adequate evidence of efficacy. That study found no major differences between a group of children with autism who received AIT and a group who listened to unmodified music. The panel's conclusion? "Because of the lack of demonstrated efficacy and the expense of the intervention, it is recommended that auditory integration training not be used as an intervention for young children with autism." (New York State Department of Health, 1999).

Sensory integration therapy has also been promoted in ARRI, although careful scrutiny of the research on this popular intervention has consistently failed to uncover any sound scientific evidence that it produces meaningful outcomes for people with autism or other developmental disorders. This was the conclusion of both the NYSDOH and the Maine Administrators of Services for Children with Disabilities (MADSEC) review panels; in fact, the NYSDOH literature search found 29 articles on the use of sensory integration therapy, none of which met criteria for adequate evidence of efficacy. Readers are also referred to articles on sensory integration therapy in this issue of *Science in Autism Treatment*, as well as critical reviews of sensory integration therapy by Arendt, MacLean, and Baumeister (1988), and Shore (1994).

Megadoses of vitamin B6 and magnesium have long been promoted in ARRI, with repeated assertions that they are totally harmless. In contrast, a blue-ribbon panel of reviewers convened by the National Institute of Mental Health stated in 1995 that although most studies of vitamin B6 with children with autism reported improvements, "... all studies had

serious methodological problems, and there is no good rationale for using vitamin B6 with this population" (Singh, Ellis, Mattila, Mulick & Poling, 1995). Another recent review of research on vitamin B6 and magnesium in the treatment of autism concluded, "The majority of studies report a favorable response to vitamin treatment. However, interpretation of these positive findings needs to be tempered because of methodological shortcomings inherent in many of the studies" (Pfeiffer, Norton, Nelson, & Shott, 1995). The NYSDOH panel reached similar conclusions, and further noted that chronic use of vitamin B6 has been reported to cause peripheral neuropathy (weakness, numbness, and/or unpleasant sensations in the extremities).

Our values statement clearly stipulates that ASAT will support any treatment that is shown to be effective or promising in methodologically rigorous studies—not in speculative articles, or testimonials, or surveys, or opinion polls.

Children who receive even modest doses over long periods may be at risk for this side effect, but no long-term studies have examined that possibility (New York State Department of Health, 1999). This side effect was also noted by Dr. Victor Herbert in a chapter of the book *The Health Robbers: A Close Look at Quackery in America* (also see Quackwatch.com). Dr. Herbert stated the facts plainly: "Many substances that are harmless in small or moderate doses can be harmful either in large doses or by gradual build-up over many years. Just because a substance (such as a vitamin) is found naturally in food does not mean it is harmless in large doses" (p. 24).

The most recent treatment to be hailed in ARRI as an effective treatment for autism is the hormone secretin. However, when secretin was presented in a series of media reports last year as “possibly the most important discovery in the history of autism,” there was not a single controlled study to support the claim that it produced large, functionally significant improvements in children with autism—merely anecdotal reports. Secretin has been approved only for single-dose administrations to test gastrointestinal functioning in adults, with cautions about its potential for producing severe allergic reactions. Whether it is safe to use with typically developing children—much less children with compromised central nervous systems—is unknown. Concerned parents, physicians, and other professionals

How much time can parents, professionals, and people with autism afford to spend in pursuit of every treatment that someone claims is a “dramatic development” or “breakthrough?”

pointed out these facts, along with the fact that the secretin preparation contains other ingredients that have known harmful side effects, including neurotoxicity (see *Science in Autism Treatment*, Vol. I, Spring, 1999). The American Academy of Child and Adolescent Psychiatry issued a policy statement on March 3, 1999 to promote awareness that the use of secretin has not yet been proven safe in controlled studies. Several reputable investigators have conducted or are conducting evaluations of secretin with children with autism; it will be interesting to see what is revealed when placebo and observer bias effects are well controlled, and the children’s functioning is assessed by

direct observational measures according to the standards of good science. Meanwhile, secretin continues to be promoted in ARRI.

Could it be that the aforementioned professional organizations, reviewers, scientists, and parents, along with ASAT, have all been dead wrong about the scientific evidence for these treatments, while Dr. Rimland is correct in asserting that “...several treatment approaches... clearly meet the criterion of scientific validation,” including vitamin and dietary interventions? Is the conclusion reached by the NYS-DOH and MADSEC panels and other reviewers that ABA is the best-validated treatment currently available really ludicrous, false, absurd, nonsensical, counterfactual, indefensible, distorted, and wrong, to use some of Dr. Rimland’s terms?

Readers must answer those questions for themselves, of course, but in so doing we urge consideration of the facts presented above, as well as the following: Contrary to Dr. Rimland’s statements, there are many accepted scientific methods for evaluating treatment effects besides double-blind group studies. For instance, there are several other types of research designs in which a group of individuals who receive a specific treatment is compared with a group who receive no particular treatment, or another treatment altogether. There are also single-subject research designs, in which treatment-no treatment comparisons are made with the same individual, and replicated with that individual and others. Moreover, treatment effects can—and should—be measured by methods other than the laboratory assays of substances in the blood or urine that Dr. Rimland espouses. In fact, such substances may have little or no bearing on how an individual listens, learns, walks or talks. Changes in those and other aspects of functioning must be measured directly. There are numerous scientific

methods for doing so. Finally, contemporary ABA is much more rich and complex than the “operant conditioning” methods Dr. Rimland says he observed in the 1960s, and has a substantial research foundation. [See sidebar]

There are some other important questions we urge readers to consider carefully. How much time can parents, professionals, and people with autism afford to spend in pursuit of every treatment that someone claims is a “dramatic development” or “breakthrough?” How much private and public money continues to be poured into these “options” before they fizzle out (or not), only to be supplanted by another one? How many children are being used as subjects in uncontrolled, unmonitored “experiments” by people who have been encouraged to “press all the buttons,” and

We hold that parents have not only the right to choose treatments for their children, but also the responsibility to make sure that those treatments are based on sound evidence of safety and effectiveness.

“try anything and everything that you think may be helpful?”

Contrary to the implications of the ARRI editorial, The Association for Science in Autism Treatment is not against choice. We are for *informed* choice. In the realm of autism treatment, ASAT believes that true choice is possible only when those making the choices are fully informed of the degree to which each treatment has been shown to be, or feasibly promises to be, effective and safe in peer-reviewed scientific studies. It is a contradiction of the notion of informed choice to fail to fully disclose the gaps or weaknesses in the evidence about any treatment, and to publicly attack those who raise legitimate questions about the quality of that evidence.

Nor is ASAT an "ABA only" organization. On the contrary, many of the parents and professionals on ASAT's Board would like nothing better than to find an effective alternative to the hard, expensive, and time-consuming work entailed in ABA programming. ASAT's Advisory Board draws from a variety of disciplines in the biological and behavioral sciences. Our values statement clearly stipulates that ASAT will support any treatment that is shown to be effective or promising in methodologically rigorous studies—not in speculative articles, or testimonials, or surveys, or opinion polls.

At the same time, ASAT does not suggest that anyone's statements about treatments for autism should be taken at face value, including ours. ASAT's Board and supporters include many professionals and parents with a great deal of knowledge about autism. Nevertheless, we do not claim any exclusive moral high ground because we are parents, or that we have all the answers because we are professionals. We know that we all need to be vigilant about the limits of our knowledge. And, no matter how numerous our supporters, we will not cite opinion polls to buttress our positions. Popularity has never been any guarantee of truth.

ASAT encourages parents and professionals to become informed about the quality of the evidence that supports all claims about autism treatments. We hold that parents have not only the right to choose treatments for their children, but also the responsibility to make sure that those treatments are based on sound evidence of safety and effectiveness. Those who support ASAT's efforts do so because they know that humane, ethical application of scientific knowledge is necessary to ensure that everyone who is ill, disabled, young, or otherwise vulnerable receives the best possible care. Children and adults with autism deserve no less.

— ASAT Board

HOW CREDIBLE IS THE RESEARCH ON ABA TREATMENT FOR AUTISM?

In his editorial in ARRI, Dr. Rimland referred to only one ABA study, the Lovaas (1987) study of early intensive behavioral intervention. The fact is that something in excess of 550 controlled studies published in the professional literature since the 1960s document the effectiveness of ABA methods for producing functional improvements in many skill domains of people with autism. (DeMyer, Hingtgen & Jackson, 1981; Hingtgen & Bryson, 1972; Matson, et al, 1996).

Dr. Rimland characterized methods of measuring treatment effects in ABA studies as "subjective" and "soft," and implied that they are not "scientifically replicable." That is inaccurate. In ABA studies, treatment effects are measured by repeated direct observations of individuals over time. Treatment procedures as well as potential treatment effects are defined in observable, measurable terms. Specific procedures are followed to control for biases inherent in human observations, including verification by trained independent observers, objective measurement criteria, reliability measures, and others. These methods have been well described in the behavior analysis and therapy literature for decades, replicated in thousands of published studies, and widely adopted by many behavioral scientists. Indeed, since autism is currently behaviorally defined and diagnosed, behavioral observation and measurement methods could be incorporated into evaluations of virtually all types of treatments for autism.

Single-subject research methods are among the hallmarks of applied behavior analysis. Controlled comparisons of a particular treatment with no treatment, or with another treatment, are made with the same individual(s). In the single subject approach, treatments are deemed effective only if they result in *functional improvements* for the individuals involved—effects that are typically much larger, in terms of measured gains, than effects that are found to be statistically significant in comparisons of averaged data in group research studies. Single-subject designs are particularly useful for evaluating treatment effects in typical education and treatment settings, since most practitioners are concerned with individual clients or learners, rather than groups. Because individuals diagnosed with autism often differ considerably from one another, the intensive focus on the individual also makes single-subject research methods well-suited for studying treatment effects in autism.

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LOOKING AHEAD

I was flipping through recently developed photographs looking, as I usually do, for the pictures that stand out. I'm always looking for those special images that capture a precious expression, a beautiful face or a special memory. As I searched through the pile of mediocre pictures, I came across one that brought tears to my eyes.

My son Daniel was perched in a tree looking down at his Daddy with a smile of recognition and delight. My husband Tom was affectionately returning Daniel's smile, echoing this delight. For most families, this scene would be typical; but parents of children with autism know just how precious it is to have your child recognize your presence, and to return your love and affection.

I painfully remembered the rejection we had once felt from Daniel. Years ago he showed no recognition of us, and in fact seemed to be tortured by us. Our presence was interfering, rather than comforting. Our touch seemed to be painful, rather than soothing. Our affection triggered anxiety, rather than comfort. Our voices were meaningless, rather than familiar. Our love was unnoticed, unwanted and seemingly unnecessary.

We picked Daniel up out of his crib in the morning, and he would push our faces away. We desperately wanted a good morning kiss,

but instead we were greeted with what Tom termed "our good morning slap in the face." We longed to feel a connection from Daniel, some sort of recognition that we existed in his world. We wanted to be known, we wanted to be loved, and we wanted desperately to be needed. It was quite obvious, though, that we were not needed. I remember many tearful conversations when Tom would say "I just want him to love me back."

Things have changed dramatically. Daniel recognizes us, seeks us out and returns our affection. It didn't just "happen," though. Like everything else in his life, Daniel needed to be systematically taught. He needed to be taught that I am called Mommy, and Tom is called Daddy. He needed to be taught to tolerate our touch, to attend to our voices, to understand our words, to recognize our faces, and to respond to our affection. And we needed to be taught how to establish ourselves as meaningful in Daniel's life. Through years of training and practice, we were eventually able to teach Daniel how to love us, and we were able to create within Daniel a desire to



Daniel Mannion with his father, Tom

be with us. His love, hugs, kisses and smiles are now a part of our everyday lives.

In the day-to-day struggles of teaching Daniel, trying to meet his needs, structuring his time and guiding his behavior, the road ahead can still seem so long. I am often overwhelmed by how far we still need to go, and frustrated by the uncertainty of where we'll end up.

On this day, though, as I looked at that photograph, I reminded myself of just how far we have come. I realized that sometimes, I need to look back, to find the strength to look ahead.

— Kathy Mannion

Do you have a child with autism?

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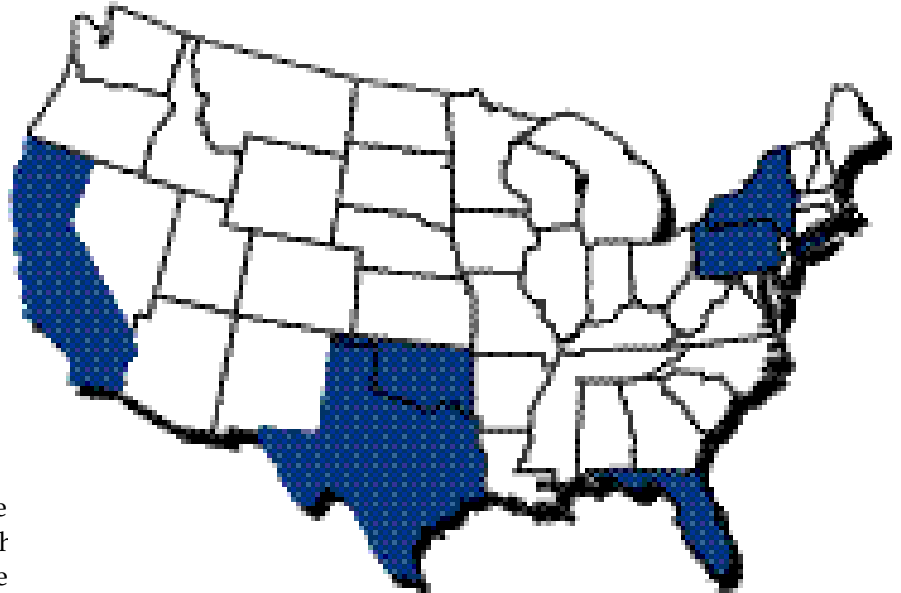
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UPDATES:

CREDENTIALING

Directors of the Behavior Analyst Certification Board (BACB) have developed eligibility standards for BACB certification, as well as criteria by which individuals currently certified under existing state programs can transfer certification to the BACB. Eligibility standards for BACB certification are substantially equivalent to those used by the successful Florida Behavior Analysis Certification Program, and by other existing state certification programs in California, Texas, Pennsylvania, New York and Oklahoma. As in the state programs, the BACB will certify individuals at the bachelor's degree level (Board Certified Associate Behavior Analyst) and at the master's degree and above level (Board Certified Behavior Analyst). The BACB will administer its first examination to eligible candidates at the Washington D.C. Association for Behavior Analysis Convention in May, 2000.

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Dr. James Johnston of Auburn University, representing the Association for Behavior Analysis; Dr. Jon Bailey of Florida State University, representing State Associations for Behavior Analysis; Michael Hemingway, Director of the Florida program, representing Florida; Dr. Jerry Shook, Executive Director of



BACB; and Dr. Catherine Maurice, representing consumers of behavior analysis services.

For current information on all aspects of the BACB, go to www.BACB.com.

— Gerald L. Shook, PhD, CBA/FL,
Executive Director

AACAP ISSUES POLICY STATEMENT OF SECRETIN

On March 3, 1999 the American Association of Child and Adolescent Psychiatry issued the following Policy Statement on the use of secretin in the treatment of autism.

POLICY STATEMENT

American Association of Child and Adolescent Psychiatry

Secretin in the Treatment of Autism

Approved by the Council on March 3, 1999

Secretin is a polypeptide neurotransmitter involved in digestion. This agent has been approved by the Food and Drug Administration for use in the diagnosis of gastrointestinal problems in adults; repeated

use has not been approved by the FDA. Several anecdotal reports have suggested that secretin may ameliorate some of the symptoms of autism and one open study of three children has been reported. The mechanism of action is unclear; there are not yet appropriate controlled studies which support the use of this agent, nor has it been determined that it is safe for repeated administration. Accordingly, the use of this agent should be considered unproven and experimental.

Given the severity of autism, parents and family members are often willing to try treatments that promise improvement, but are

unproven. Such treatments are usually based on anecdotal reports that are often unsubstantiated by more rigorous research; the short term change reported may be non-specific and unsustainable.

Families should be helped to make informed decisions about their use of alternative or nonestablished treatments, including careful consideration of risks and benefits. The American Academy of Child and Adolescent Psychiatry supports the study of all promising treatments by well designed research.

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ASAT'S GREEN, OTHER BOARD MEMBERS AT CHICAGO CONVENTION

"It is clearly a mistake to underestimate the power of pseudoscience and the pseudosolutions it offers," warned Gina Green, PhD during her Presidential address to the Association for Behavior Analysis in Chicago. "Pseudoscience poses such a threat to society that it behooves the entire scientific community to do everything it can to counter its influences."

Speaking to more than 2100 attendees at the May convention, Green urged scientists to prevent the "New Age from devolving into a new Dark Age, and to find real solutions to increasingly difficult problems."

Green announced that the Association for Behavior Analysis is participating in efforts to have the US Congress declare the first decade of the new millennium as the Decade of Behavior. The Decade of Behavior will "set the stage for behavioral science to make gains in research funding, training opportunities, and public visibility comparable to gains made by neuroscience during the Decade of the Brain," Green said. Advancements are likely in the areas of "Brain-behavior relations, behavioral pharmacology, behavioral development, autism and

other disabilities, education, and translating laboratory models of clinical problems into application."

The importance of science was a theme echoed by ASAT board members Richard Foxx, John Jacobson, Suzanne Letso, and Catherine Maurice during a panel discussion on science and the treatment of autism. Each of these speakers emphasized the need for both parents and professionals to seek out accurate, objective information about autism and its treatments. "Resources are scarce," Jacobson said, "and we cannot afford to use precious time or funds on interventions with little or no basis in empirical data."

During the opening event, ASAT Board member Gerald Shook was honored by the Society for the Advancement of Behavior Analysis with SABA's Public Service award. Other SABA award recipients included Ogden Lindsley, Juan Robinson Lopez, Patricia J. Krantz and Lynn McClannahan.

ASAT Board members including Sigrid Glenn, John Jacobson, Lawrence Lee, James Mulick, Gerald Shook and Bridget Taylor participated in presentations on topics exploring functional communication, supported inclusion,

credentialing, and building a behavior analytic educational program, among other issues.

"It has been estimated that only about 5% of the population today has basic scientific literacy skills," Green pointed out during her speech. This can have "rather frightening implications when you consider that our lives are increasingly affected by the findings and products of science."

At the conclusion of the Presidential address, the audience responded with a standing ovation and expressions of support. "Dr. Green has tirelessly challenged the psychological, educational and medical communities to bring the objective measures of science to autism treatment for over 25 years," said Joan Davin, Executive Director of ASAT. "Yet at the same time, Dr. Green maintains the compassionate perspective that good science is a tool to help people with autism learn skills that will enable them to lead rich lives. The Association for Science in Autism Treatment and the Association for Behavior Analysis are most fortunate to benefit from Gina Green's integrity, scholarship and compassion."

ASAT

ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

Thank you...

Steve and Sally Bradford and Kassie Davin for their ongoing support of ASAT's travel expenses.

Fed Ex for their generous corporate support.

ASAT HONORS PA DIRECTOR OF SPECIAL EDUCATION



ASAT Board Member, Richard Foxx, PhD presenting award to William Penn, EdD

ASAT was pleased to honor William Penn, EdD, Director of the Bureau of Special Education, Pennsylvania Department of Education, for his outstanding efforts to advance science-based treatment and education for Pennsylvania citizens with autism. The award was made at a reception in Dr. Penn's honor on August 8, 1999, during the Pennsylvania Summer Autism Institute. In addition to ASAT Board members and invited guests, National Institutes of Child Health and Human Development Director Duane Alexander, MD, and Penn State's Jack Neisworth, PhD, expressed appreciation for Dr. Penn's commitment. Penn credited Fran Warkomski, PhD for her own significant contributions in developing the Commonwealth's first graduate-level certificate program in applied behavior analysis, in cooperation with Ed Donovan, Director of Statewide Programming for Continuing and Distance Education at Pennsylvania State University, and Gerald Shook, PhD, Executive Director, Behavior Analyst Certification Board, (BACB) Inc. This year's Summer Autism Institute, entitled "Progress Through Partnership," featured several key presentations by ASAT Board members on science-based treatment technology, and was attended by over 700 participants. In addition, 52 people participated in the behavior analyst certification coursework offered during the week-long program.

NICHHD Director, Duane Alexander, MD, with ASAT board member, Suzanne Letso and ASAT Executive Staff, Kathy Mannion and Marissa Bennett



NEW YORK, MAINE ISSUE EVIDENCE-BASED ASSESSMENTS FOR AUTISM INTERVENTIONS

Recently, the New York State Department of Health (NYS-DOH) Early Intervention Program and the Maine Administrators of Services for Children with Disabilities (MADSEC) have independently completed comprehensive, multidisciplinary reviews of the scientific evidence about interventions for autism. The NYSDOH review panel also generated evidence-based guidelines for behavioral, educational and medical assessment of young children with autism. Both reports concluded that applied behavior analysis is scientifically validated as an effective

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intervention for autism. The New York review panel recommended that "principles of applied behavior analysis (ABA) and behavior intervention strategies be included as an important element of any intervention program for young children with autism" (Guideline Technical Report, p. IV-15).

One or both panels concluded that there is no or insufficient scientific evidence to support the efficacy of other interventions, including sensory integration therapy, Greenspan's "floor time," vitamin therapy, special diets, hormones such as secretin and ACTH, and anti-

yeast therapies. These were not recommended as primary interventions for children with autism. Still other interventions, including facilitated communication, auditory integration training, and intravenous immune globulin therapy were found to be ineffective or harmful in sound studies, so one or both panels recommended that they not be used with children with autism.

The New York clinical practice guidelines focus on children under three years of age, but the review panel noted that its recommendations are also applicable to somewhat older children. MADSEC's report is intended to be a guide for educators of children birth through 20.

According to the NYSDOH report, "The impact of clinical practice guidelines for the Early Intervention Program will depend on their credibility with families, service providers, and public officials. To ensure a credible product, the NYSDOH elected to use an evidence-based, multidisciplinary consensus panel approach. The methodology used for these guidelines was established by the Agency for Health Care Policy and Research (AHCPR). The DOH selected the AHCPR model for this effort because it is an effective, scientific, and well-tested approach to guideline development" (Guideline Technical Report, p.xi).

The (MADSEC) autism task force also took an evidence-based approach to assessing interventions for autism. They noted that "an intervention for individuals with autism can be characterized in one

of four ways:

It may be objectively substantiated as effective based upon the scope and quality of scientific research. It may anecdotally show promise, but is not yet objectively substantiated as effective using controlled studies and subject to the rigors of good science. It may have been repeatedly subjected to the rigors of science, which leads numerous

Authors of the New York and Maine reports made it clear that, at present, the recommendations of their respective panels are not mandatory standards of practice. Both panels emphasized, however, that evidence-based practice guidelines provide the necessary foundation to improve the effectiveness of services to individuals with autism, and to ensure accountability.

researchers to conclude that the intervention is not effective, may be harmful, or may lead to unintended consequences. It may be without scientific evaluation of any kind." (Report of the MADSEC Autism Task Force, p. 3).

MADSEC includes among their recommendations that those who determine or provide autism inter-

ventions “. . .ensure services for children with autism are based upon scientifically validated procedures; ensure that services to children with autism include systematic instruction procedures focusing on both the acquisition of skills, and the decrease/elimination of interfering behaviors”; and “require ongoing evaluation of autism interventions using controlled studies and subject to the rigors of good science. Ongoing evaluation should minimally include a credible method of evaluation, and criteria for determining whether to terminate or continue the intervention” (Report of the MADSEC Autism Task Force, p.7).

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that evidence-based practice guidelines provide the necessary foundation to improve the effectiveness of services to individuals with autism, and to ensure accountability.

To Order:

The NYSDOH Clinical Practice Guideline: Autism/Pervasive Developmental Disorders. Assessment and Intervention for Young Children (Age 0 - 3 years) actually consists of three documents. These are available as a set for \$21.50, or separately; the cost includes postage.

The Guideline Technical Report contains complete information about the project, including evidence tables listing all articles reviewed, a full report of the research process, and the full text of all recommendations (\$13).

Report of the Recommendations includes background information, the full text of all recommendations, and a summary of the supporting evidence (\$9).

Quick Reference Guide includes summary background information, and a summary of the major recommendations (\$7.50).

Call the NY State Department of Health, Early Intervention Program, Health Education Services at 518-439-7286, or log onto <http://www.health.state.ny.us/nysdoh/eip/menu.htm>.

The Report of the MADSEC Autism Task Force can be purchased by calling 207-626-3380. Cost is \$20, which includes postage.

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NIMH Research Roundtable Meeting, Washington, D.C.

Left to right – Jane Steinberg, PhD, Acting Director, Division of Extramural Activities, NIMH; Gina Green, PhD, Director of Research, New England Center for Children; Steven Hyman, MD, Director, NIMH; Mrs. Joan Davin, Acting Executive Director, ASAT; Lawrence Lee, MD, ASAT

VIEW POINT:

SENSORY INTEGRATION THERAPY IN AUTISM

By A. Mervyn Fox

In the 1970s, Jean Ayres proposed a theory of brain function emphasizing sensory integration, and devised the Southern California Sensory Integration Tests. These tests were used to evaluate behaviors which Ayres regarded as evidence of vestibular dysfunction. The vestibular system is theorized to have a role in "subjective awareness of body position and movement in space; postural tone and equilibrium; and stabilization of the eyes in space during head movements" (Fisher, 1991). Vestibular receptors are stimulated by movement of the head and by gravity. This stimulation is provided by swinging in net hammocks, and other suspended equipment (Fisher, 1991).

Ayres' theory needed its own language. Some terms, such as tactile defensiveness, were new. Others, such as dyspraxia, vestibular-proprioceptive dysfunction, perceptual difficulties, and communication problems were adapted from conventional neurology.

Sensory integration disorder is diagnosed based upon observations and interpretations of behavioral abnormalities, as is autism. However, unlike autism, there is no empirical support for the existence of the disorder independent of Ayres' theory-specific tests. Hence, the diagnosis of sensory integration disorder employs circular logic: without the belief system, there is really no evidence for the theory.

However, SI practitioners do base their interventions, upon their theory. SI devotees will attribute almost any undesirable behavior or characteristic to sensory integration failure, and SI interventions are recommended almost indiscriminately. In the case of motor clumsiness, a number of methodologically sound studies have failed to demonstrate significant gains after intensive theory-based interven-

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tions, including sensory integration (Polatajko, Kaplan & Wilson, 1992).

Some of Ayres' speculations might be borne out by careful study; but if so, it would not confirm her theory about the effect of sensory integration therapy on brain functioning. For example, some behaviors such as head banging, covering the ears, or high rates of motor activity might serve to provide a child with autism some

stimulation, or they might have a calming effect. Alternatively, however, these behaviors might function to gain attention or to escape something the child finds difficult, such as social interactions. The methods of applied behavior analysis, not sensory integration therapy, enable us to determine the functions of such behaviors, and to alter the environment appropriately.

It may also be important to teach a child with autism to tolerate certain stimuli, such as sounds or the textures of certain foods or clothing. But that can be best accomplished using the well-validated behavioral method of systematic desensitization, not SIT.

Do children "need" sensory integration? Parents of autistic children face an almost intolerable dilemma when professionals suggest that sensory integration therapy should be a required part of the child's program. Parents may not have been offered validated strategies. It may be suggested to parents that without sensory integration therapy, there is little hope their child will make significant progress.

Does sensory integration therapy improve the systems of autism, or somehow rectify the "root cause" of autism? It is unconscionable for a therapist to suggest that by suppressing associated behavior the autism is improved; yet such suggestions, often tacit and implicit, are not infrequently made. Parents

of autistic children, and other intervention consumers, have a right to the same sort of "informed consent" which is mandatory before taking medication or undergoing surgery. Parents must understand the natural history of the disorder without the intervention in question. All therapeutic choices should be disclosed to parents, as well as possible side effects. Parents also need to be informed consumers of research, understanding the weakness of anecdote and the strength of controlled experiments.

What does the research say about sensory integration? Early critiques of SI generally advocated more research, since favorable studies were few and all utilized inadequate methodology. (Ottenbacher & Short, 1985; Tickle-Degnen, 1988). A multi-center combination of two efficacy studies found SI effects to be no more effective than other, more traditional interventions for learning disabled children (Kaplan, Polatajko, Wilson & Faris, 1993). In a comparison with perceptuo-motor training, SI therapy was associated with some gain in motor planning, but there was no generalization to cognitive or academic skills, or to self-concept (Humphries, Wright, Snider & McDougall, 1992). A recent authoritative review that cited over 105 studies raised serious doubts about the validity of SI therapy as a treatment for learning disabled children (Hoehn & Baumeister, 1994), and by extension for any other groups diagnosed as having sensory integrative dysfunction. It concluded that current research may in fact be sufficient to declare SI therapy not merely unproven, but a demonstrably ineffective primary or adjunctive remedial treatment for learning disabilities and other disorders.

Despite this overwhelmingly contrary scientific evidence, SI advocates continue uncritically to promote the therapy they provide. A recent popular promotional work which is often recommended to parents of mildly autistic children makes no reference to any of the scientific critiques (Kranowitz, 1998).

It is not up to the scientific community to disprove SI theory. Rather, it is up to SI devotees to produce convincing evidence—if not for their beliefs, at least for the efficacy of their interventions.

It is not the scientist-clinician's role to diminish or extinguish hope. Best clinical practice in autism combines realism with optimism.

It is not up to the scientific community to disprove SI theory. Rather, it is up to SI devotees to produce convincing evidence—if not for their beliefs, at least for the efficacy of their interventions.

When resources are limited (and when are they not?) it is ethical to provide evidence-based interventions in preference of those dependent only upon belief. Sensory integration therapy is not always pleasant for the children, and it may easily take time away from proven interventions, which attack the core symptoms of autism rather than the non-specific halo of dysfunction generated by the autistic brain. Lost hopes, lost investments and lost faith in professionals are not insignificant side effects.

SI practitioners are well-meaning and have a strong, sincere belief in what they do. However, profes-

sionals practicing evidence-based treatment must be highly skeptical of SI. In addition, individuals responsible for the disbursement of scarce resources should favor an evidence-based approach to decision making as well.

We need to challenge SI practitioners to offer some evidence of effectiveness stronger than their own opinions or the occasional anecdote.

—A. Mervyn Fox MB BS FRCPC
FRCPCH DCH is Medical Director of a large regional children's rehabilitation center in London, Ontario and an Associate Professor of Pediatrics, Psychiatry and Occupational Therapy at the University of Western Ontario.

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VOICES

Dear Folks at ASAT:

I just received your first newsletter and devoured it cover to cover with tears streaming down my face. What you are doing is so very, very important.

I am a mother of two children: Harry (9) and Georgia (7), both of whom have autism. I sobbed when I read the quote from Kathy Mannion "had it not been for science, I don't know where my sons would be today. Because of pseudoscience, I will never know where they could have been today". To see my anguish in print, described so succinctly, was overwhelming.

Three years ago my husband Bernie and I, along with Donna & David Cattell-Gordon, founded The Virginia Institute of Autism (VIA). We are a school serving sixteen children with autism in central Virginia. We utilize applied behavior analysis (ABA) instructional techniques to teach our kids one-to-one. Our dream is to one day be a replication site for Princeton Child Development Institute. I was excited to read about the Certified Behavior Analyst & Certified Associate Behavior Analyst programs. With the overwhelming demand for ABA services it is clear that ensuring competency of providers is paramount.

Congratulations to all of you who are dedicating yourselves to this crucial mission. I'm behind you 1000%.

Sincerely in Science,

Alison Hormel Webb

Charlottesville, VA

PS: I never write letters.



Alison Hormel Webb's children, Georgia and Harry

I just got my first issue of the ASAT newsletter. I have been quite concerned about all the hype about secretin, and I'm glad that the ASAT board took a position of caution on this issue. After reading Dr. Rimland's newsletter, I felt the enthusiasm over secretin was premature.

Questionnaires are really another way of gathering "testimonials" or "case reports" and are subject to a lot of bias, even though one can do a fair number of statistics on the results. I think the ASAT newsletter should do an issue on research methods, reprising the chapter in the Maurice/Green/Luce book. This might clear up some of the confusion on the "quality of the evidence".

I am a neurologist and the father of an 8-1/2 year old girl with autism. I plan to attend Conference 2000 in NYC. I hope Continuing Education credits will be available for professionals.

Thanks for all your work for our kids with autism!!

Peter Bridgman MD
Waterville, ME

Continuing Education credits will be available!

SAVE THE DATE

CONFERENCE 2000

March 9 - 10, 2000
First International Conference
Science in Autism Treatment
Marriott Marquis Hotel - New York City

PRESENTATION TOPICS

BRAIN PLASTICITY • PLAY & LEISURE SKILLS • FOOD SELECTIVITY
THEORY OF MIND • PHARMACOLOGY • TOILET TRAINING • DIAGNOSIS
NEUROIMAGING • IMMUNOLOGY • NATURALIZING LANGUAGE
CLINICAL PRACTICE GUIDELINES • ADVOCACY & LEGAL ISSUES
CREDENTIALING BEHAVIOR ANALYSTS • UNIVERSITY TRAINING MODEL
LANGUAGE ASSESSMENT & INTERVENTION • APPLIED BEHAVIOR ANALYSIS
PEER RELATED PROGRAMMING • COST BENEFIT OF EFFECTIVE TREATMENT
GENETICS • SKILL ACQUISITION/BEHAVIOR REDUCTION • FLUENCY
INVESTIGATING THE "SOCIAL BRAIN" • AUGMENTATIVE COMMUNICATION
EVIDENCE BASED AUTISM TREATMENTS

...and more

FEATURED SPEAKERS SCHEDULED TO APPEAR

William Ahearn, PhD

Shahla Ala'i-Rosales, PhD

Stephen Anderson, PhD

Carl Binder, PhD

James Black, MD, PhD

Deborah Fein, PhD

Richard Foxx, PhD

Joanne Gerenser, MA CCC-SLP

Sigrid Glenn, PhD

Gina Green, PhD

John Jacobson, PhD

Ronald Kallen, MD

Glenn Latham, PhD

Karin Lifter, PhD

Catherine Maurice, PhD

William McMahon, MD

James Mulick, PhD

George Niemann, PhD

James Partington, PhD

Alan Poling, PhD

Marie Bristol Power, PhD

Joe Reichle, PhD

Raymond Romanczyk, PhD

Robert Schultz, PhD

Gerald Shook, PhD

Helen Tager-Flusberg, PhD

Bridget Taylor, PsyD

Rick Tessel, PhD

...and more

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