

SCIENCE IN AUTISM TREATMENT

Premiere Issue

Spring, 1999

THE NEWSLETTER OF THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

ASAT FORMED TO MEET CRITICAL NEEDS

The Association for Science in Autism Treatment (ASAT) was formed by parents and professionals dedicated to ensuring that children and adults with autism lead lives filled with dignity, purpose, peace and independence.

It is probably safe to assume that most parents and professionals who care about people with autism support this goal. But difficulties—even conflicts—may arise when people of good intentions differ with each other over the means of achieving goals they share.

Currently, the field of autism is marked by a high degree of such conflict. Rather than ignore it, it may be a good idea to spell out clearly what ASAT is about so that others have the opportunity to support our mission based upon a clear understanding of that mission. We stand for science in autism treatment.

Two Historical Trends

To understand why ASAT has chosen such a focus, a brief description of the historical context in which we are launching our cause is in order. That history reveals two dominant trends:



Learning to read at New Jersey's Alpine Learning Group

- A troubling parade of ineffective treatment models, miracle cures and faddish “breakthroughs.” Often these are sensationalized by the media, fueled by the anxious love of mothers and fathers, and adopted readily by service providers, in spite of the absence of any evidence of effectiveness. The most

persistent of these ineffective treatments are those that are based upon outdated psychodynamic theories, wherein autism is seen as an emotional wound. In the past, this putative emotional fragility was treated largely through psychoanalysis; today it is addressed through play therapy. This model

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WELCOME TO SCIENCE IN AUTISM TREATMENT

The premiere issue of *Science in Autism Treatment* marks an exciting milestone in the brief history of ASAT. The mission of this publication is to provide accurate, science-based information about autism and treatments. The editors of and contributors to *Science in Autism Treatment* are committed to delivering a rational alternative to the pseudoscience and authoritarianism that seem to typify information about this increasingly common disorder. Consequently, our reporting is meticulously reviewed for accuracy by ASAT's Advisory Board. These pages contain information you can trust. **Keep it. Share it. Use it.** Together, we can change the lives of the people we love who have autism. Welcome to *Science in Autism Treatment*.

– Lora Perry, *Managing Editor*

ASAT MISSION STATEMENT

ASAT's mission is 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.



continues to be offered by those who see their role as understanding and reassuring a frightened child.

- The tendency of many in the professional community to ignore or even denigrate treatments that do have good, supportive data. Indeed, the very notion of data, outcome measures or objective validation simply does not figure in much of the published literature on autism intervention. Rather, the norm has been for many authorities to posit a speculative cause for autism, and propose an equally speculative remediation of the condition, based largely upon personal belief, or “clinical intuition.”

Looking Back

What gave rise to these trends? Probably a multitude of factors, too complex to analyze at any length here. However, we can at least identify some of the major formative influences on treatment politics.

- From the moment autism was identified in the 1940s, erroneous assumptions about its etiology have flourished. Children with autism are often beautiful, with no obvious physical impairment or distinguishing features. This physical normalcy is but one of the factors providing a fallow ground for the idea of autism as an emotional wound.

- Universities and medical schools provide little training in how to evaluate the effectiveness of proposed autism treatments; hence, there is a troubling scientific illiteracy on the part of the people from whom we most often seek such guidance. In fact, until recently, medical attention was focused largely on endlessly redefining the symptoms of autism, rather than on any effective treatment.

- In the absence of accurate, objective information about effective

autism interventions and outcome statistics, our educational system has failed to meet the profoundly complicated learning needs of our children. Many educators have low expectations for children with autism, in part because educators are seldom trained to overcome autistic behaviors that interfere with learning—behaviors which may include crying, screaming, self injury and aggression. Consequently, learning does not take place.

- In the culture at large, there are many negative assumptions



ASAT board member Marissa Bennett and son, Justin

about the very nature of science. Some people tend to equate science with all that is cold, dangerous and controlling. This problem is exacerbated by the inability of many scientists to translate their discoveries into the vernacular. Instead, many rely upon an impersonal, mechanistic jargon to convey their findings about human beings. In contrast, treatments cloaked in a language of quick fixes, nurturing love or instinct have strong emotional appeal.

- In some quarters, there is strong resistance to the very notion

of treatment itself, analogous, perhaps, to similar arguments raging around other conditions, such as deafness. Rather than seeing autism as a fundamental disability—one that strips a human being of many

We need to challenge every one of these experts with at least as much skepticism as we bring to the purchase of a used car.

possibilities and promises—some advocates fiercely insist on a policy of acceptance of autistic individuals for who they are, and decry any attempts at treatment as oppression.

- There are serious problems creating turmoil within the field of behavior analysis, a field scientifically validated as effective in the treatment of individuals with autism. These include frequent misapplication of behavioral science by unskilled or unethical practitioners; the absence of nationally accepted standards of competency; and the claims of a few individuals to be the only providers of worth.

- And finally, there is the seductive rhetoric of an ideology that keeps trumpeting such appealing concepts as open-mindedness, choice, an eclectic approach, and options.

Unfortunately, open-mindedness without healthy skepticism, choice that is not informed choice, and options embraced for the sake of option alone only prolong the sad history of failed treatments.

Disastrous Consequences

But whatever the causes, the resultant dismissal of treatments backed by science has disastrous consequences for our children’s already fragile future. When children are

denied effective treatment, there is a double tragedy: their potential for growth and learning is thwarted; and they often become the subjects (or objects) of repeated, ineffective experiments as parents pursue all possible flickers of hope.

Continue These Trends?

All these political ideologies have survived, however, largely because both professionals and parents have allowed their survival. It is a natural human tendency to follow personalities, especially charismatic ones, rather than dry, scientific lit-

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erature. We tend to seek warm and compelling stories, rather than cold statistics. We are very willing to accept the expertise of people who base their recommendations upon anecdote and opinion, their “thirty years in the field,” their clinical judgment; and we are often bored with people who talk about data, numbers, controlling for variables, and the like.

A New Path

But after the debacle of the Bettelheim era, where one man’s opinion was allowed to dominate autism treatment and shatter fami-

lies, it is clear we need to challenge every one of these experts with at least as much skepticism as we bring to the purchase of a used car, let alone to life-shaping decisions for our children. We need to add critical thinking to compassion, or we will continuously follow every self-confident savior and every sad dead end.

So where does that leave us, we who love our children, and who wish to make decisions based upon both tenderness and tough thinking? It leaves us in need of reliable guidance, founded on facts, not fame.

ASAT

It is that pressing need that has given rise to ASAT’s mission: to disseminate scientifically sound information about autism and treatments for autism. But, recognizing that access to accurate information is only half the battle, ASAT will promote effective training models in university settings. And recognizing that treatments will only be as effective as the people providing the treatments, ASAT will support the development of professional credentialing, and standards of education and treatment.

Facts, Not Fads

As a guiding principle, ASAT intends to evaluate claims about treatment from the perspective of sound, scientific reasoning. ASAT is locked into no one treatment for autism, but we will not hesitate to let people know which treatments are supported by solid scientific research, and which are not—be they from medical, behavioral or educational science. We are seeking to move public awareness away from personalities and fads, and into an understanding of the

true hope that scientific research has produced, and will continue to produce, for all of our children.

By Whose Authority?

How will ASAT provide such guidance? Not through any personal opinion or belief of ours, but through the help of an exemplary Advisory Board drawn from both the biological and behavioral sciences—men and women whose strongest credential is not their popularity, but their adherence to the highest standards of scientific integrity. ASAT claims no authority other than what reason and science have supported. We have no illusions about the fallibility of human opinion. But one thing we do know is that children and

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

adults with autism, and the people who love them, can be helped. We know autism is treatable, but only when people get the information and help they need.

Science for People

And finally, it is important to note that ASAT will use the tools of science to achieve our mission, but we are not working for science as an end. The end, for all of us, lies not in the mere furthering of human knowledge or human technology. The end lies in the lovely faces of our children, in their sweet eyes, in their profound worthiness. It is science that guides us, but love that inspires us, and we will not fail our children.

—CM

Science, Pseudoscience and Antiscience:

WHAT'S THIS GOT TO DO WITH MY KID?

"Your child has autism"...with those words, a parent's world comes crashing down.

What to do? Choosing a treatment is one of the most important decisions the parents of a person with autism will ever have to make. How do parents find truly effective treatment for their child? In an ideal world, the person who dropped the autism diagnosis on a family would provide the answer. But the unfortunate fact is that many who make this diagnosis are not well-informed about the wide array of autism treatments, and the degree to which these treatments have proven effective (or not). So until the day comes when parents can count on data-based professional guidance, they will need to become very discerning about the various treatments, therapies, and programs that are claimed to be effective for autism. The same applies to those who are concerned with helping families get effective services. There is a need to do a lot of homework, and to do it quickly. Why the urgency? Because the stakes are high, and every moment is precious.

Children and adults with autism can learn, and there are effective methods for helping them develop useful skills and lead happy, productive lives. At the same time, research has shown that many currently available interventions for autism are ineffective, even harmful, while others have simply not been



Jason and Joshua Perry, twin sons of ASAT board member Lora Perry

tested adequately. Every moment spent on one of those therapies instead of effective intervention is a moment lost forever. Besides, common sense suggests that it is wise for parents and professionals alike to invest in interventions that can be reasonably calculated to produce lasting, meaningful benefits for people with autism—that is, interventions that have withstood scientific testing.

As parents and professionals seek information about autism treatments, they discover a long and perplexing list of "options," many of them promoted by sincere, well-meaning, persuasive people. Everyone claims that their favorite treatment works, and parents and practitioners are often encouraged

to try a little bit of everything. This can be very appealing to people who are seeking *anything* that might help. How does one choose wisely? To quote the late Carl Sagan, "The issue comes down to the quality of the evidence." So the first step is to find out exactly what evidence is available to support claims about autism treatments. But all evidence is not created equal. How does one sort pure hype from solid proof, wishful thinking from rigorous testing?

Approaches to answering fundamental questions about how the world works can be grouped into three broad categories: science, pseudoscience, and antiscience. Science uses specific, time-honored tools to put hunches or hypotheses

to logical and empirical tests. Some of those tools include operational definitions of the phenomena of interest; direct, accurate, reliable, and objective measurement; controlled experiments; reliance on objective data for drawing conclusions and making predictions; and independent verification of effects.

*Why the urgency?
Because the stakes are
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is precious.*

Science does not take assertions or observations at face value, but seeks proof. Good scientists differentiate opinions, beliefs, and speculations from demonstrated facts; they don't make claims without supporting objective data.

In contrast, pseudoscience tries to lend credibility to beliefs, speculations, and untested assumptions by making them *appear* scientific—for example, by using scientific jargon, endorsements from individuals with “scientific” credentials, perhaps even some numbers or graphs. But instead of objective measurements from well-controlled experiments, pseudoscientists offer testimonials, anecdotes, and unverified personal reports to back up their claims. Antiscience is the outright rejection of the time-tested methods of science as a means of producing valid and useful knowledge. The extreme antiscientific view is that there are no objective facts; all knowledge is made up of personal interpretations of phenomena.

Pseudoscientific and antiscientific treatments and approaches for various conditions, including autism,

abound. They are promoted enthusiastically, not in peer-reviewed scientific journals, but in materials published by their promoters, such as newsletters, videotapes, books, advertisements, and the Internet. These treatments have several distinguishing features (see sidebar). Some may seem benign at first glance, but that can be misleading. Over the years, many such treatments have proven to have very harmful physical and emotional side effects. They also exact a great societal toll by diverting

*The issue comes
down to the quality
of the evidence*

—Carl Sagan

precious resources from effective treatments and sound research, raising false hopes, and perpetuating illusions (for some examples, see the September 1998 issue of the *New England Journal of Medicine*, and the book *Crazy Therapies*, listed below).

Parents and professionals can protect people with autism from the harms of bogus and ineffective treatments by exercising healthy skepticism, and asking several questions of everyone who claims to have an effective intervention for autism: What is the intervention, precisely? Exactly what is it supposed to do? Have its effects been tested in controlled experiments using direct, objective measures? If so, were those studies published in peer-reviewed scientific journals? What did studies show about positive effects and negative side effects?

Did the effects carry over beyond the immediate treatment setting? Is there another scientifically validated treatment that is similarly effective but has fewer negative side effects? Who will administer this treatment, and how can I be sure they are qualified to do so? How will its effects on this individual be evaluated, and by whom? What will happen if we do nothing? Listen to the answers, but don't take them at face value. Seek out published research on the treatment, and, if necessary, someone with expertise in scientific research methodology to help you evaluate it. Also take note when no answers—and no solid supporting studies—are provided. What is not known or said matters, too.

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When families seek treatment for a child diagnosed with cancer or diabetes, they aren't simply given a long list of interventions that someone somewhere believes to be effective, and told to choose from that list on their own.

long list of interventions that someone somewhere *believes* to be effective, and told to choose from that list on their own; they can usually expect to be informed about treatments that are based on sound scientific research. Why settle for anything less when the diagnosis is autism?

—Gina Green, PhD and
Lora Perry, MS

FOR ADDITIONAL INFORMATION ON SCIENCE, PSEUDOSCIENCE AND ANTISCIENCE

Barrett, S., & Jarvis, W. (Eds.) (1993). *The health robbers: A close look at quackery in America*. Buffalo: Prometheus Books.

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

Randi, J. (1982). *Flim-flam!* New York: Prometheus Books.

Sagan, C. (1995). *The demon-haunted world: Science as a candle in the dark*. New York: Random House.

Shermer, M. (1997). *Why people believe weird things: Pseudoscience, superstition, and other confusions of our time*. New York: W. H. Freeman.

Singer, M.T., & Lalich, J. (1996). *"Crazy" therapies. What are they? Do they work?* San Francisco: Jossey-Bass Publishers.

Taubes, G. (1993). *Bad science: The short life and weird times of cold fusion*. New York: Random House.

Vyse, S. (1997). *Believing in magic: The psychology of superstition*. New York: Oxford University Press.

www.skeptic.com – Web site for *Skeptic* magazine and the Skeptics Society

PSEUDOSCIENTIFIC THERAPIES:



(adapted from the
American Arthritis Foundation)

1. High "success" rates are claimed.
2. Rapid effects are promised.
3. The therapy is said to be effective for many symptoms or disorders.
4. The "theory" behind the therapy contradicts objective knowledge (and sometimes, common sense).
5. The therapy is said to be easy to administer, requiring little training or expertise.
6. Other, proven treatments are said to be unnecessary, inferior, or harmful.
7. Promoters of the therapy are working outside their area of expertise.
8. Promoters benefit financially or otherwise from adoption of the therapy.
9. Testimonials, anecdotes, or personal accounts are offered in support of claims about the therapy's effectiveness, but little or no objective evidence is provided.
10. Catchy, emotionally appealing slogans are used in marketing the therapy.
11. Belief and faith are said to be necessary for the therapy to "work."
12. Skepticism and critical evaluation are said to make the therapy's effects evaporate.
13. Promoters resist objective evaluation and scrutiny of the therapy by others.
14. Negative findings from scientific studies are ignored or dismissed.
15. Critics and scientific investigators are often met with hostility, and are accused of persecuting the promoters, being "close-minded," or having some ulterior motive for "debunking" the therapy.

SECRETIN: ANOTHER “BREAKTHROUGH” TREATMENT?

Over the last several months, the potential of secretin to treat autism has been passionately promoted. Consistent with ASAT’s mission to provide accurate, science-based information, we took an objective look at the research available to support dramatic claims of effectiveness.

Does the hormone secretin, manufactured from pig intestines, really represent yet another “breakthrough” in autism treatment? The Association for Science in Autism Treatment (ASAT) urges extreme caution in prematurely embracing claims that it does. So far, sound scientific support for the use of secretin to treat autism is nonexistent. It has been approved only for single-dose administrations to test pancreatic function in adults. Safe dosage levels for children have not been determined, and nothing is known about side effects because the necessary controlled trials have not been conducted.

Secretin is being promoted as a treatment for autism on the basis of anecdotes, testimonials, and a published report of three uncontrolled case studies (Horvath, Stefanatos, Sokolski, Wachtel, Nabors & Tildon, 1998, *Journal of the Association for Academic Minority Physicians*, Vol. 9, No. 1, pp. 9–14). This report states that three children improved physically and behaviorally some time after receiving secretin, but omits specific information about how those changes were measured. The authors acknowledge that the children involved were participating in educational programming and other treatments when they received secretin and thereafter.

Since the study was not controlled, it is impossible to determine whether the changes—if changes did indeed occur—were due to secretin, or to the other interventions.

The literature being used to market secretin reflects an almost callous disregard for the most basic principles of objective evaluation, scientific testing, and ethics. Instead of hard data, “belief” and unverified personal accounts are offered as the basis for proclaiming secretin “possibly the most important discovery in the history of autism.” Pressure is put on parents

If the claim that secretin benefits people with autism is indeed plausible, it will withstand careful scrutiny and repeated testing.

to subject their children to repeated injections of an untested substance whose side effects are completely unknown. Some of those who are promoting secretin most avidly are those who stand to profit monetarily from its sale. The *Canadian National Post* reported recently that the initial story about secretin on U.S. television created a black market for the substance, pushing the cost for a small vial from \$100 to \$5,000 – \$10,000 in some areas. Some physicians are reported to charge exorbitant fees for secretin injections, and the demand has made it difficult for legitimate researchers to get enough of the substance to test it properly.

Over the past few decades, autistic children have been subjected to countless experimental, sometimes dangerous, and often outrageous treatments. Most have entailed enormous expenditures of money, time and emotional energy. Almost none have stood up to sound, scientific testing. Parents, professionals, investors, and anyone who wants to make considered, wise decisions for autism or any other condition would do well to consult Quackwatch.com, a physician-managed Web site devoted to alerting consumers about organizations and individuals who regularly promote questionable health practices.

There are effective, scientifically validated methods for helping children and adults with autism. The best-documented of these to date is intervention based upon the principles of applied behavior analysis (ABA). But scientific research into other treatments is ongoing, and much more is needed. Dr. Marie Bristol-Power and others at the National Institutes of Health are to be commended for demanding that all treatments for autism undergo rigorous scientific testing. The Association for Science in Autism Treatment also supports scientific investigation of all promising interventions for autism, both biological and behavioral. If the claim that secretin benefits people with autism is indeed plausible, it will withstand careful scrutiny and repeated testing. It is through critical assessment, not chimerical speculations and sensationalism, that true breakthroughs in the understanding and treatment of autism will be accomplished.

–ASAT Board

WALL STREET JOURNAL

PUBLISHES SECRETIN PARENT/PROFESSIONAL STATEMENT

The following letter was published in the *Wall Street Journal* on April 16, 1999 in response to a WSJ article on secretin published March 10, 1999. The letter is reprinted here with the permission of the authors.

Dear Editor:

As parents of autistic children and as professionals who treat these children on a daily basis, we find it necessary to respond to your article of March 10, 1999, "New Hampshire Mother Overrode Doubts on New Use of Old Drug." We are concerned that a reputable, high-caliber publication such as the *Wall Street Journal* would add to the sensationalism surrounding the purported therapeutic use of

Although Secretin has been used for years as an aid in diagnosing gastrointestinal disturbances, and is approved as such for adults, its safety and efficacy in children have never been tested.

secretin for children with autism. This "therapy" lacks published controlled studies to support its use, though many such studies are underway. In addition, although secretin has been used for years as an aid in diagnosing gastrointestinal disturbances, and is approved as such for adults, its safety and efficacy in children have never been tested. Nothing is known of

the potential long-term negative effects of secretin. The hormone was first promoted on the basis of anecdotal reports of a child who has never been formally diagnosed with autism (Parker Beck). The fact that this subject appears at all in *The Wall Street Journal* tends to serve as an endorsement for secretin, making it seem a legitimate and valid therapy. Parents who read the article may have little knowledge of the necessity for controlled studies in the scrutiny of new treatments.

We are also concerned about what parents are NOT told during their inquiries regarding secretin:

1. The reported improvements are, for the most part, temporary, and may not be measurable by standard cognitive, social, and language testing methods.
2. Since secretin is a porcine product, there is a possibility that repeated doses in humans could lead to antibody formation against secretin by the immune system (as was the case with insulin) and eventual lack of effect.
3. There is a theoretical potential for long-term adverse effects from secretin such as pancreatic "burnout" due to repeated intravenous doses which are high compared to physiologic levels.
4. Secretin is currently prepared in Sweden following the same methods used in the 1970s when it was first extracted from

porcine intestines. Although it is relatively safe to say that secretin is free from viruses endemic to pigs, it is also true that the preparation cannot be 100% "pure," that other smaller pieces of proteins are contained in the vial. These extraneous proteins would be an added burden to the child's immune system, which may react to them.

5. Secretin is not the sole physiologically active ingredient in the infusion. It requires a stabilizer, cysteine hydrochloride. This cysteine component is also biologically active in the central and peripheral nervous systems. The amount of cysteine in one vial of secretin is negligible for

The amount of cysteine in one vial of secretin is negligible for adults, but is significant for children... cysteine acts as an excitatory neurotransmitter and has been shown to be toxic at high concentrations.

adults, but is significant for children. This fact will become a problem for "practitioners" administering three and four vials at a time, since cysteine acts as an excitatory neurotransmitter and has been shown to be toxic at high concentrations.

6. After three to five days, much of the cysteine injected is metabolized to taurine, a compound

which has a generalized depressant effect on the nervous system, and may be responsible for the calming parents have reported after secretin therapy.

7. People are assuming that secretin has a direct action on the central nervous system, but it has never been shown that this hormone crosses from the bloodstream into the brain at all. Secretin's stabilizer cysteine, however, does cross into the brain.

The events surrounding secretin have mirrored the history of autism "research" in that parents, at great emotional and financial expense, are encouraged to try some new "therapy" that has no real data to

support its use. Most therapies have turned out to have little or no effect. It would help legitimate research efforts if highly regarded newspapers could avoid adding to the feeding frenzy of secretin. The shortage of this hormone created by the publicity of the "Dateline" broadcast last October pushed the black market price of one vial to \$5000, as reported in the *Canadian National Post*, even though the cost to manufacture and ship, according to Ferring Pharmaceuticals, is \$175. Until positive and lasting results are shown by controlled studies, great caution should be exercised in advocating for or using secretin. The off-label use of secretin has become a money-making venture for "practi-

tioners" preying on a desperate population of parents.

Respectfully,

Susan L. Connors, MD., Hopedale, MA

Dorothy E. Crowell, Housatonic, MA
Deborah Fein, Ph.D., University of Connecticut

William Chey, M.D., D.Sc., University of Rochester Medical Center

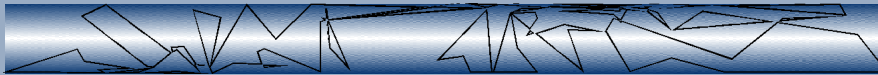
Peter Murad, Somerville, MA

Gina Green, Ph.D., New England

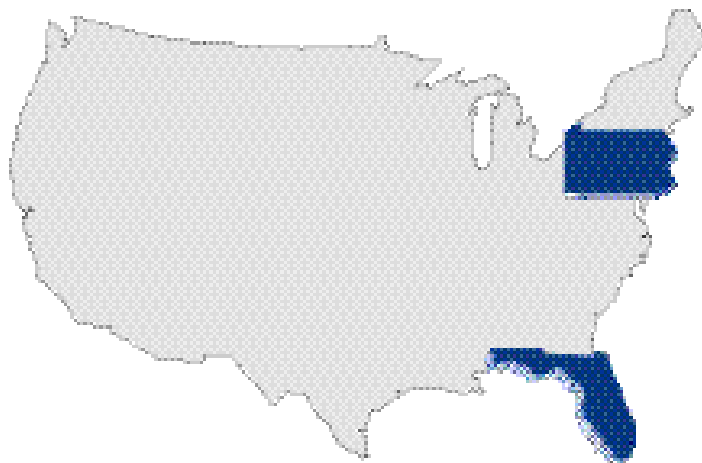
Center for Children, Southborough, MA

Steve Auster, M.D., Worcester, MA

P.S. The information on cysteine is scheduled to be published as a Letter to the Editor in the July issue of the *Journal of the American Academy of Child and Adolescent Psychiatry*.



BY 2000



The Behavior Analyst Certification Board, Inc. (Board) has been formed to develop, promote and implement a voluntary certification program for behavior analyst practitioners across the United States and, eventually, other nations. The Board will establish uniform content, standards and criteria for the Behavior

Analyst Certification Board credential. It will also ensure that its program meets the legal standards established through state, federal and case law; the standards of the national Organization for Competency Assurance; and the "best practice" and ethical standards of the behavior analysis profession.

The Board will develop its certification model based upon the successful Behavior Analyst Certification Program operated by the State of Florida. The Florida program has been in operation for 15 years, and helps to ensure the competency of practitioners through stringent requirements for appropriate professional experience; formal education; passing a professionally-developed written examination; and continuing education.

The ABA Council has endorsed the formation of the Behavior Analyst Certification Board, and has provided financial support to aid the development process.

The Board seeks to administer the certification exam to eligible candidates at the Washington, DC ABA Convention in 2000.

—Gerald Shook, PhD

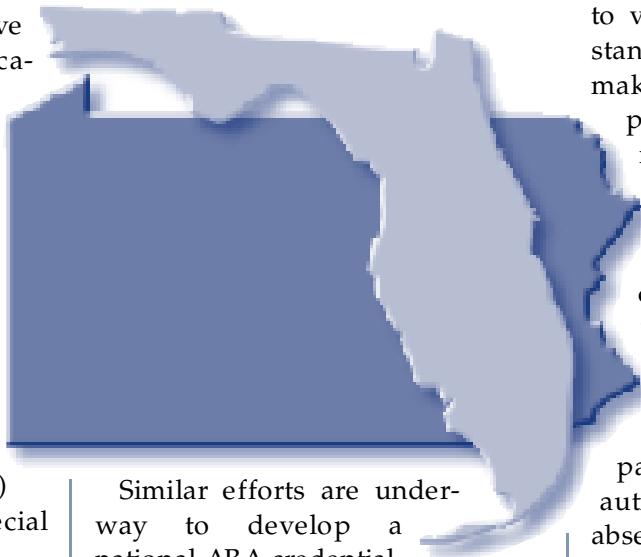


CERTIFICATION HELPS PARENTS, PROFESSIONALS ENSURE MINIMUM LEVELS OF COMPETENCY

At least 26 professionals have voluntarily earned certification under Pennsylvania's one-year-old Credentialed Behavior Analyst (CBA) or Credentialed Associate Behavior Analyst (CABA) program. Modeled after a similar process used in Florida since the 1980s, the Commonwealth's program was developed under the leadership of William Penn, Ph.D., Pennsylvania Department of Education (PDE) Director of the Bureau of Special Education.

Responding to requests from parent organizations, Penn convened a focus group in June 1997 consisting of parents, advocates and educators, as well as staff from universities, state agencies and the medical community. The group determined that the PDE should place greater emphasis on educational models that are scientifically validated as effective for children with autism, and devote more funding to such programs. Specifically, the group sought to increase the number of professionals trained in applied behavior analysis (ABA), and to improve the quality of ABA services by ensuring the competency of practitioners.

Dr. Fran Warkomski headed the credentialing project for PDE, drawing upon the expertise of Dr. Gerald Shook and Associates of Florida. To ensure adequate training for practitioners seeking certification, Warkomski and Shook collaborated with Ed Donovan of Penn State University to develop the Commonwealth's first graduate-level certificate program in ABA.



Similar efforts are underway to develop a national ABA credentialing program also based upon the Florida model. As in Florida and Pennsylvania, national certification will be voluntary. Consumers of ABA services will not be prohibited from hiring or retaining existing providers who do not chose to

Certification is voluntary. Consumers of ABA will not be prohibited from hiring providers who do not choose to become certified.

However, certification provides assurance that the provider has met specific standards of competency.

become certified. However, certification provides consumers with assurance that the provider has met specific standards of competency.

"Pennsylvania has taken a leadership role in the Northeast to ensure competency-based training of staff to provide effective treatment of our residents who have autism," Warkomski said. "We look forward

to voluntary national credentialing standards, and hope other states make this critical research-based practice commitment by ensuring the availability of university training in ABA."

"Credentialing will go a long way toward helping consumers choose providers who are truly competent to help our children," according to Carol Javna, PhD, Clinical Psychologist. Dr. Javna is the parent of two children with autism, ages 7 and 10. "In the absence of such standards, virtually anyone can claim to be qualified to conduct this treatment. I hope that soon, through training and credentialing efforts such as these, parents of autistic children will not face the sorrow that we have had to face—knowing what is effective for our children, but being unable to find professionals who know how to deliver it."

For more information about the Pennsylvania ABA certificate program offered through Penn State, log on to www.outreach.psu.edu/statewideprograms or contact Kay Partenhelmer, Continuing Education, Pennsylvania State University, 118 Keller Building, University Park, PA 16802-1300, phone 814-865-3443.

Florida and Pennsylvania allow non-residents as well as residents to apply for certification. To obtain eligibility requirements and an application booklet, contact Teresa Bixler, Central Instructional Support Center, 6340 Flank Drive, Suite 600, Harrisburg, PA 17112, phone 717-541-4960. To contact Gerald Shook and Associates, call 850-668-8757.

—Pam Dawson

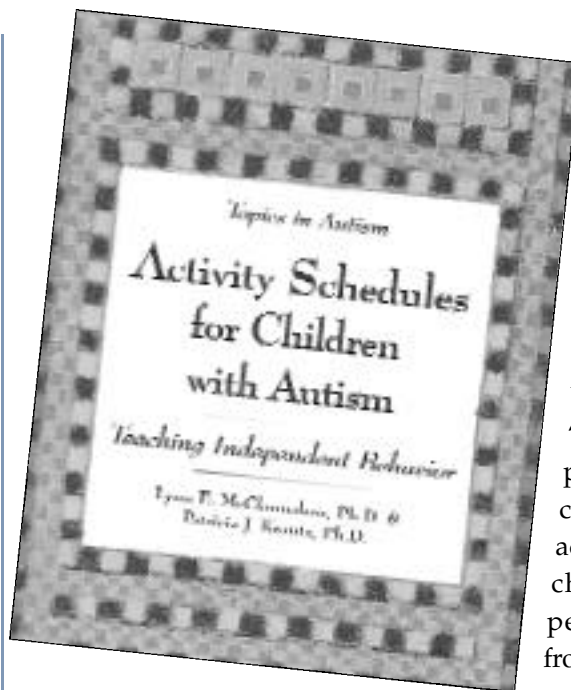
Unwrapping the Gifts of Independence and Choice Activity Schedules for Children with Autism: Teaching Independent Behavior

Lynn E. McClannahan, PhD & Patricia J. Krantz, PhD, Woodbine House, 1999 (toll free number 800-843-7323).

Currently, popular works on autism intervention tend to fall into a few broad categories including, but not limited to:

Group A: Opinion books, in which assertions about treatment are based largely upon the author's personal beliefs, masquerading as received wisdom (what "we" supposedly know or do not know about autism). Little if any quality research is cited to back up such opinions: authors tend to cite not peer-reviewed studies, but their own fame, their "thirty years in the field." Typically, such works trumpet the appealing but unfortunately vacuous premise that there are "many options" for treating autism, while offering no clear description nor solid scientific support for such options. Such opinion-based works have contributed heavily to the lack of effective services for autistic children.

Group B: Coping books, whose authors (typically not parents themselves), claim nevertheless a deep understanding of the impact of autism on families. These authorities see their job as analyzing various parental personality types and their respective abilities to cope with an autism diagnosis. While such coping is a laudable goal, it is a matter of some debate whether the great majority of these books actually achieve that end, or



whether they simply prolong the Bettleheimian model of psychoanalyzing parents, instead of offering concrete help for their children.

Group C: Descriptive books, in which the authors set about seeing how many new and different ways they can reformulate, redescribe, and recategorize the symptoms of autism. As a parent I know remarks, "How many ways can you peel an onion?"

In this bleak literary landscape, the occasional work that is actually data-based, and strongly anchored in both credible research and solid clinical experience, is a rarity. When such a work also offers concrete help for people, it becomes a blessing.

McClannahan and Krantz have written such a book. Their *Activity Schedules for Children with Autism* offers practical, step by step advice on how parents and teachers can help children to learn and to function with greatly reduced adult supervision. Using the teaching tool called "activity schedules"—sets of pictures or words that cue a child to engage in a sequence of activities—they demonstrate how children can be taught to independently engage in everything from playing with toys to holding social conversation without reliance on constant adult prompting. For the many parents who cannot access good, center-based programs for their child, this book represents a generous source of truly expert knowledge and concrete assistance. For those who want to increase their effectiveness in working with autistic children, this work provides clear discussion and clear examples of an important teaching tool. Chapters cover topics of assessing a child's readiness to use activity schedules, as well as constructing, introducing, monitoring and fading such schedules. Apparent throughout the work is the authors' deep and caring commitment to increase independence, choice and social interaction for the children they serve.

— CM

ASAT BOARD MEMBER/PARENT KATHY MANNION TESTIFIES BEFORE NATIONAL COMMITTEE ON BEHALF OF CHILDREN

The National Bioethics Advisory Committee (NBAC) has drafted human research guidelines that may impact autism research, and consequently, autism treatment. The guidelines call for changes to current federal regulations, as well as the creation of a new standing national oversight panel.

Drafted over the course of more than a year, the guidelines seek to protect people who cannot consent to treatment from the effects of certain high risk studies that do not offer potential direct benefit to the subject. But that laudable goal may have unintended consequences. Researchers, parents and the National Institutes of Health's (NIH's) National Institute of Mental Health (NIMH) have expressed concern that the recommendations may impede important research on

Good, ethical, humane scientific research has yielded promising advances in the treatment of childhood autism.

mental disorders. NBAC Chairman Harold Shapiro disagrees, contending that "appropriate ethical constraints" will result in more public support of research.

ASAT board member Kathy Mannion is among those who testified before the NBAC about how the proposed guidelines may negatively impact research on children with autism. Following are her remarks:



ASAT board member Kathy Mannion and sons (from left to right, Brian, Patrick, Michael, Daniel)

"Good morning. My name is Kathy Mannion, and I represent two of my children who are incapable of representing themselves. My sons Brian, age 9 and Daniel, age 8, have autism.

Living with autism is typically a lifelong struggle for both the child and the family. Children are unable to communicate or understand language. They are unable to learn even the simplest things on their own. They engage in ritualistic, often bizarre, sometimes violent, and even self-injurious behavior, and they require constant supervision and teaching. For families like mine, life is often something to survive rather than something to enjoy. Autism is not episodic; there are no periods of normalcy; it is, indeed, a constant.

My purpose today is to convey to you the tremendous need for ongoing and scientifically sound

research in the field of autism. Although the vast majority of persons with autism would be considered incapable of understanding or providing informed consent, good, ethical, humane scientific research has yielded promising advances in the treatment of childhood autism. But this is only because parents and guardians have been free to allow their children to participate in such research.

I learned many years ago while working at Memorial Sloan-Kettering Cancer Center that whenever there exists a condition with no known physiological cause or cure, desperation and vulnerability pave the way and create a haven for pseudoscience. This is in fact true of autism. It is a field that is littered, and more accurately dominated, by pseudoscience. The presence of ongoing and scientifically sound investigation is sorely

lacking and the absence of the dissemination of accurate, scientifically validated information has not only allowed pseudoscience to flourish, but to prevail. This results in precious time lost and resources wasted.

When we first entered the world of autism, my husband and I were not at all prepared for the complex maze that we would have to navigate in order to get an accurate diagnosis and timely, effective intervention for Brian and later Daniel. They were evaluated by a vast array of professionals and were labeled speech impaired and language delayed. The unanimous recommendation was for both of them to be placed in a generic early intervention program. Although they began intervention at less than two years of age they made little, if any, progress in the first three years of remediation.

During this time my questions were governed by judgment honed in medical science from my tenure at Memorial Sloan-Kettering. Yet when I asked about a definitive diagnosis, we were told one could not be made. When I asked what the research indicated on types of interventions and their effectiveness, we were told that no research was available. The more I pushed for answers and information, the more frequently I was referred to various support groups. It was clear to me that in the field of mental health, the focus was more on helping parents to cope rather than providing them with the information they need to make informed decisions about the best possible care and intervention for their children.

It took us over three years to finally access what scientific investigation had already proven to be

the most effective intervention for children with autism. Once Brian and Daniel began to receive effective intervention, they not only began to learn but they began to thrive. Had it not been for science, I don't know where they would be today. Because of pseudoscience, I will never know where they *could have been* today.

Brian and Daniel and countless other people with autism did not have the cognitive ability to provide informed consent to any type of scientific investigation. If parents and legal guardians do not have the right to provide consent for

"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."

them, people with autism will be almost categorically deprived of the benefits that scientific investigation provides.

However, scientific investigation is the only hope that people with autism have. As a parent, I applaud the efforts of this committee in trying to protect the rights of those who are not capable of protecting themselves. I would respectfully ask, however, that the committee give careful consideration to autism and developmental disabilities where, before treatment, there are no episodes of normalcy and informed consent cannot be granted, unless by a parent or guardian. Without this proviso, scientific study in this field would be virtually eliminated.

I ask that in your efforts to protect our children, you do not unintentionally deprive them of the one and only hope that they and their families have for a better life and a brighter future.

—Kathy Mannion

ASAT WOULD LIKE TO THANK...

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