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ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

SCIENCE IN AUTISM TREATMENT

Vol. 2 No.1

Spring 2000

THE NEWSLETTER OF THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

Surgeon General Endorses Intensive Behavioral Intervention for Autism

United States Surgeon General David Satcher, MD, PhD, has endorsed intensive behavioral intervention for individuals with autism. *Mental Health: A Report of the Surgeon General* states, "Thirty years of research demonstrated the efficacy of applied behavioral methods in reducing inappropriate behavior and in increasing communication, learning, and appropriate social behavior."

The report is available on the world wide web at www.surgeongeneral.gov/library/mentalhealth/chapter3/sec6.html#autism. The report can also be ordered by calling 1-877-9MHealth, or by writing to Mental Health, Pueblo, CO 81009.

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DIAGNOSIS: AUTISM

A Family's Journey To Obtain Effective Treatment

"It's very apparent to us that this is autism." The developmental pediatrician's words hit me like a nuclear bomb as I sat in the examination room cradling my 19-month-old son. I wanted to run far away with my son in a futile attempt to protect us from everyone, and from the autism that loomed ahead of us like a dark storm cloud.

After performing a battery of diagnostic procedures, the professionals who made the diagnosis recommended that we immediately place Justin in their therapeutic nursery program. The program treated children with various disabilities and, at the time, we didn't realize that there were any other options available to us. We were assured by the professionals that this was the appropriate placement for our son.

In the months that followed, we faced frustrating obstacles and heartbreaking decisions. The process of securing an accurate second opinion was fraught with misdiagnoses by several professionals of varying disciplines. We discovered it was necessary for us to become "immediate experts" in the field of autism, since the professionals to whom we turned for information lacked even a rudimentary knowledge of autism and its treatment options. We then had to address the challenge of securing appropriate and beneficial treatment for a con-

dition we knew nothing about and received no treatment guidance for; all the while, we as parents were enduring the agony of grieving the loss of our "normal" child before he was barely a child. We felt that we were racing the clock, as every day our beautiful little boy slipped further away from us, and from the typical development he had displayed just a few short months before.

Justin floundered in his nursery program. The program was staffed by a very attentive special education teacher and two aides assigned to eight children. Speech and occupational therapies were also provided. However, my son preferred isolation and engaging in bizarre behaviors over group activities like circle time, singing songs and doing arts

continued on page 3



ASAT Executive staff member Marissa Bennett and son, Justin.

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EDITORIAL*Is It All About Recovery?*

My twin sons Jason and Joshua are six years old. They have not recovered from autism. Does that mean they never will? Maybe, but I'm not willing to call it yet. Here's why:

First of all, I have reason to seriously disagree with people who say recovery from autism is not possible. What is recovery from autism? At its most basic level, it is when the individual once met but no longer meets the criteria for autism in the *Diagnostic and Statistical Manual of Mental Disorders*, the DSM-IV. As a parent, I will not dignify the contention that if the child recovers, he was obviously once misdiagnosed. The circular logic inherent to the idea that autism is by definition a life-long disorder will never get us anywhere. Emerging data show we may need to change that definition.

Secondly, there is nothing wrong with pursuit of the ideal. People who say we should let autistic individuals be autistic have never faced my sons' self injurious and perilously aggressive behaviors. No one can convince me it is humane or ethical to accept that these behaviors are simply part of my sons' natures.

Thirdly, we know much more today about how individuals with autism can learn. I will not look to the past as an indication of what the future will bring. If we decide recovery is unattainable after the age of six and we stop trying, it will be a self-fulfilling prophesy. I might also point out that one of the children in the original Lovaas study required six years of treatment before he no longer met the diagnostic criteria for autism.

Am I in denial? No. I will love my children forever, autistic or not. I will also always help them to reach their full potential until I draw my last breath. For more than 50% of individuals with autism, the big news is not that there is a "limited window of opportunity" for recovery. The big news is that all individuals with autism, regardless of age, can make significant, meaningful progress toward rich and independent lives using scientifically validated treatment methods. If recovery happens along the way, so much the better.

- Lora Perry, Editor

The big news is that all individuals with autism, regardless of age, can make significant, meaningful progress toward rich and independent lives using scientifically validated treatment methods.

ASAT MISSION STATEMENT**THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT WILL:**

- Disseminate accurate, scientifically sound information about autism and treatments for autism; and
- 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, and
- 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.

VOICES

Dear ASAT:

I just had to share this with someone! My special education teachers have been trying to toilet train a nine year old young lady with autism for years. We have hired consultant after consultant, and tried everything we could think of. This year we attended Conference 2000, and Richard Foxx's presentation on toilet training. We also bought Foxx's and Azrin's book, *Toilet Training Individuals With Developmental Disabilities*. Using what we learned from these sources, our special ed teacher taught this child to self-initiate for the toilet in just a few days. The mother saw her child ask to use the toilet for the first time, and I thought she was going to cry. It's now been several weeks, and "Julie" seems to be nearly independent with her toileting. Thank you from all of us!

*Shirley Tawney, MS
 Director of Special Services
 Bath, Maine*

I just attended the ASAT conference last week. I am totally perplexed as to how ASAT can be accused of doing or representing anything less than the justice that children deserve. For years we have wasted the lives of children with autism by pursuing such ridiculous treatments as facilitated communication, "swing" therapy, magical pills, etc. . . . ASAT promotes the use of evidence-based treatment, in the hopes that parents will see beyond the gimmicks and miracle wonders. Unfortunately, everyone wants to make a buck. People prey upon parents. If ASAT is able to deter one parent from these gimmicks and unsubstantiated claims, they will fulfill their mission.

I'm sure this will evoke some unpleasant responses. Oh well. I'd love to introduce you to the 18, 16, 11, 13 and 10 year old "kids" that I work with. Let me show you what sensory integration, facilitated communication and fad diets have done for them. They are all on waiting lists for residential treatment facilities, have no functional communication skills, are not toilet trained, and live with families who are absolutely terrified of their own children. Oh, and the "experts" who helped their parents and consulted for these children will no longer see them because they are too hard to handle.

ASAT will receive my undying support in the name of these children.

*Michelle MacPeck
 John F. Murphy Homes
 Auburn, Maine*

Internet post, forwarded to ASAT. Used with permission of the author.

It is very important for my students to be up-to-date on science-based information on autism, especially in my country, where old psychiatric approaches still thrive. I'm very positive and hopeful about your motto: "We will not fail our children." (Well, it could be a motto). Thank you very much, and my best wishes to ASAT.

We'd love to hear from you!
 Write us at ASAT@autism-treatment.org.

*Dr. Roosevelt R. Starling
 Department of Psychology
 FUNREI, Brasil*

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Creating a System to Develop Effective
Treatment Practitioners for the New Millennium**
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SHAHLA ALA'I-ROSALES, Ph.D., BCBA 20-ASAT-19

**Behavioral Assessment and Empirically
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**Incorporating Peers in the Treatment
of Children with Autism:
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and crafts. Justin's discomfort with the school environment and being separated from me would cause hours of crying. As the other children began to make progress, it seemed that my son had not benefited from intervention at all. I remember thinking that I wished Justin needed such little help as was available in his nursery program. It was very apparent that Justin needed "something else" that was "more intensive," but I had no idea what that something else was.

We continued researching autism and treatments. We reviewed every autism program in our area and, later, the country. Unfortunately, the process became even more complicated: every question we asked was answered differently by different people, which led us down more paths to be explored. I felt the injustice of not only having to deal with the diagnosis of autism, but also that we needed to become detectives as well. There were no professionals or organizations to guide us. We were told things like, "You're the expert when it comes to your child. You will know best as to what type of intervention you feel is right for him and your family." I was aghast that the investigation and direction of treatment was being placed so squarely on our shoulders. Surely we were not the first family to deal with autism. I wondered: if our child had a terminal illness, would the recommendations for course of treatment be so subjective and elusive, or would professionals prescribe treatment proven to be effective? We were desperately looking for experts to guide us. This child was our world, and we were willing to move heaven and earth to help him, but no one could show us the way.

The literature I found was grim. Little was known about autism as a disorder, except for the symptoms individuals displayed. Outdated books and articles yielded even less in the way of treatment breakthroughs; outcomes were expected to be institutionalization, and crippling, lifelong impairments. In an effort to help evaluate early intervention programs, I began to ask for statistics on how many children with the diagnosis of autism had been successfully mainstreamed into public schools. I was told no such data were compiled. How were we to judge a program's effectiveness in treating our son's disability if we had nothing more than the assurance that the program was the appropriate placement? Even more serious, how were providers able to judge their own program's effectiveness, and where was any measure of accountability?

Eventually, I came across an article about a center-based program for children with au-

tism that utilized the principles of applied behavior analysis (ABA). The article went on to quote the program's statistics of successful transitions for some of the children to less restrictive environments. At last we felt that we had stumbled onto a promising path.

I gradually began to learn that ABA as a science had been used to teach and treat children with autism for the past 30 years with some very promising, documented results. I also discovered that while the science of ABA does not involve invasive procedures like surgery, it requires as much academic and clinical preparation of practitioners as any specialty in the medical field. I didn't fully understand the science of ABA at the time, but I realized it was the only treatment that could offer us scientifically valid outcome data and, because of that, we needed to pursue it for our child.

By utilizing ABA, first privately and eventually in a center-based program, Justin finally began to flourish. As we became more educated about ABA, it made complete sense to us that Justin was able to make such immediate and significant progress. His program was individualized to define goals designed to address his specific deficits, and to build new skills. Each goal was broken down into incremental, measurable steps. As each increment was mastered and then combined, it enabled him to master the "building blocks" for each goal. By using daily data to chart his performance, accurate decisions could be made regarding the direction of his programs. ABA was an incredibly effective way to teach Justin everything in his life, literally, aside from breathing.

Because nothing came "naturally" for Justin and he did not learn by watching others, every skill needed to be taught to him. Since he seemed to lack language comprehension (both verbal and non-verbal), Justin was unable to follow spoken directions. This also meant that before using ABA, we had no accurate way to measure how much of the world Justin was able to comprehend. By utilizing ABA programs, however, my son was able to master goals like imitating others and following directions. He also achieved a marked increase in both his receptive and expressive language. He was taught to utter sounds, then blends, then words, and finally sentences. This was done in conjunction with learning to comprehend what he is saying, as well as what is being said to him. In addition to academic goals like reading, writing and mathematics, Justin also needed to be taught basic self-help skills like using the bathroom, brushing his

teeth, going to sleep at night, remaining asleep until morning, bathing and dressing. As a parent, perhaps the most difficult thing for me to accept was that my son had to learn

*I am enabling my child,
through effective, science-based
treatment, to reach his fullest
potential now, under our
present system of knowledge.
That is my peace of mind.*

how to tolerate interaction with people, and to receive and reciprocate affection and love.

By using ABA as a teaching and treatment method, Justin continues to broaden his life and that of our family in very constructive ways. Thanks to ABA, he is able to tolerate getting his hair cut, and going to the doctor and dentist. He is learning to swim, and now enjoys outings to the movies, mall and the homes of family and friends. My son has learned how to learn.

Justin is now 9 years old and, unfortunately, remains a child acutely impaired by autism. He is a verbal child, able to express his basic wants and needs, yet he is not what one would consider conversational. My son cannot tell me about his day, or if he feels ill. We can't talk about his fears or share our hopes and dreams, but we do share an incredible love for each other and, despite autism, are able to enjoy a beautiful relationship. My son's autism has not been cured, but he continues to make significant progress. He has benefitted immensely from the course of intervention we have chosen for him. While our life is by no means easy or typical, we are not devastated by the obstacles that come our way. We know we can develop a strategy to assess the situation, and to teach Justin whatever skills are necessary to address and overcome the problem. We feel Justin's best chance of maximizing his potential will come from letting science lead us. By choosing science for Justin, we now have the security of knowing that we are doing everything we can to help him become the best that he can possibly be.

As a mother who loves her child absolutely, and wishes only the best for him, I support credible research into the possible biological causes and cures of autism. However, I also need to know that I am enabling my child, through effective, science-based treatment, to reach his fullest potential now, under our present system of knowledge. That is my peace of mind.

What is Evidence-Based Practice and Why Should We Care?

By Jeri A. Logemann

The following article is reprinted with permission from the March 14, 2000 issue of *The ASHA Leader*, a journal of the American Speech-Language-Hearing Association.

Professionals in a variety of disciplines are talking about evidence-based practice. So what is it?

Evidence-based practice means that clinicians use evaluation and treatment procedures for particular disorders and populations. Evidence-based practice also takes into account current understanding of the pathophysiology of the disorder(s) being treated, clinical expertise, and the client's preferences for treatment.

Evidence-based practice means that clinicians are using procedures that have been studied carefully and whose result have been reviewed and published. Even though our education as speech-language pathologists and audiologists has included the use of diagnostic and trial therapy, the latter does not mean that the evaluations and procedures we use with patients should not be based in evidence indicating their efficacy.

Sometimes clients, parents, and others, in desperation, "want to try anything." For example, a patient approached me via email, desperate to return to eating after a severe skiing accident. This young man had tried a number of treatment approaches with good efficacy that were unsuccessful for him and requested my opinion about trying another procedure. I indicated that I knew of no evidence that the procedure he named was successful with any patient group, let alone for his problem as he had described it, since I had not seen him in person. He emailed back in a month to say that he had requested permission from his insurance company to receive this treatment procedure, but was told that they would not pay for it as it was experimental and had no evidence of effectiveness in any population.

If we provide treatments that lack evidence to support their usefulness in a particular population of patients, we risk wasting patients' time and money, increasing their

health risks, and not being paid for our services. In the educational setting, using procedures with no efficacy puts us at risk for slowing children's progress and wasting time precious to their development and learning.

Some clinicians say, "I have good experience with a technique that has no efficacy data published in peer-reviewed journals. What do I do?" If you are using an unproven technique, you have a responsibility to collect and publish the data on its effectiveness. My advice is to collect data systematically. Be sure to control for confounding factors, such as spontaneous recovery. If you are inexperienced in designing and writing in a research mode, contact a researcher in one of our university programs who, I'm sure, would be interested in working with you.

Our professions' futures depend on the effectiveness of our treatments, not on our impressions of their effectiveness. When you go to a workshop or continuing education experience or, better yet, before you go, it's important to ask the presenter if data exist on the techniques being described and in what peer-reviewed journals you can read about the data. It is irresponsible for presenters to discuss and advocate screening, diagnostic, or treatment procedures that are not supported by such evidence. It's important that we as clinicians question the kind of data available

to support the usefulness of a technique. It's critical our patients' well-being and our professions.

Our professions are ahead of most in ever-strengthening our evidence base. Although we still don't have every bit of evidence we would like, we should be proud of the evidence we do have available to support our procedures and should consider these data as we care for patients. Each of us has a contribution to make in this area. Consider how you can collect data in the ASHA NOMS and Clinical Trials projects in your own setting. It's time to care about evidence-based practice.

To learn more about how you can participate in NOMS, contact ASHA's National Center for Treatment Effectiveness in Communications Disorders at 301-897-0101 or look on ASHA's Web site at www.asha.org/ncteed/treatment_outcomes.htm. Information on the Clinical Trials Project can be obtained by calling 301-897-5700, ext 4367.

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"Grandpa Ron", with Brian, son of ASAT Supporters Diane and Ray Olsen.

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Early Identification of Autism
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ROBERT SCHULTZ, Ph.D. 20-ASAT-15

Which Autism Treatments are Evidence-Based?
RONALD KALLEN, M.D. 20-ASAT-16

Strategies for Beginning an Augmentative Communication System: Best Practice Guidelines Derived from Recent Research
JOE REICHLER, Ph.D. 20-ASAT-17

Incorporating Peers in the Treatment of Children with Autism: Putting Research into Practice - Part I
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Catherine Maurice's Opening Remarks at Conference 2000: Science in Autism Treatment

In response to the numerous inquiries ASAT has received since Conference 2000, Science in Autism Treatment is pleased to reproduce Catherine Maurice's opening remarks in full.

The Association for Science in Autism Treatment was formed by people who shared a dream: That every family whose child received a diagnosis of autism could have access to credible information and effective treatment.

Defining that dream meant that we had to acknowledge a painful fact. Credible information and effective treatment has not been available to the vast majority of families. Instead, most of the families we knew had to wend their way through conflicting claims, internet gossip, sensational fads and strong opinions, whether grounded in facts, or not.

Treatment has for decades consisted of three major options: first we had a variety of psychoanalytic approaches, born of the assumption that autism was caused by emotional abuse, neglect, or misunderstanding of a hurting child. Under this model, a therapist tried, through play therapy or through psychoanalysis (which must have been a trick with a non-verbal child) to bond with the child, to become, in a sense, a surrogate parent. The only problem with this model, of course, is that it was based on a mistaken premise. Autism is not caused by emotional trauma or parental mishandling. The consensus, after decades of neurological research, is that it is a biological, genetic condition, that cuts across the spectrum of race, class, socioeconomic status, parenting skill or style.

Starting around the late seventies, as that type of approach began to go out of fashion (it is by no means eradicated yet), a second treatment option began to be explored. There was a rush to identify the biological cause or causes for autism, and a cure. While this is, of course, a critically important quest, it has so far resulted in a dizzying array of questionable interventions, levied on vulnerable children, sensationalized by the media, and marketed aggressively by their promoters. However, with the formation of groups such as the National Association for Autism Research, we may see one day the results of more credible research, peer-reviewed and scientifically sound. If such groups keep their standards high, and are reasonably wary of each new Lorenzo's oil breakthrough, they may very well keep alive our hope for an effective biological treatment.

For the past few decades, a third treatment option was being refined: behavioral interven-

tion. This approach was very pragmatic. It basically said: We don't know what the cause is, and we may be a long way from a cure. Let's try to teach the children whatever we can today. This approach took all tasks, from learning to get dressed to learning to talk, and broke down that task into multiple tiny steps, helping each child to master those steps at his or her own pace.

We are dedicated to speaking the truth about any treatment that has shown it works, or that shows true promise, according to standards of reason and science.

Unfortunately for all of us, behavioral intervention has been largely ignored by the psychiatric and special education establishment, who tend to dismiss it as robot training, cruel, ineffective, etc. Now, of course, since research shows that behavioral intervention can sometimes result in normal functioning for some kids, and meaningful progress for most, some of these same folks who excoriated behavioral intervention are rushing in to claim expertise in this domain. This creates other complications: namely, the publication of books that promote a superficial understanding of behavioral science, and public confusion about what constitutes quality behavioral treatment.

But even when professionals are well-intentioned, when they wish to deliver intervention that has been researched and tested, when they are genuinely humble about what they know and don't know, many are expressing frustration that they cannot get the training they desire, and parents are anguished when they can't find qualified help.

How to begin to address some of these problems? Our answer was to found an organization dedicated to disseminating research-based information about treatments for autism, to support certification standards for treatment providers, and, eventually, to establish and support model training programs for therapists – in short, to do all we could to improve the standards of care for people with autism who are alive today.

Our founding members are professionals and parents. We knew that any group purporting to screen information needed professionals renowned for their high standards of scientific objectivity. We knew that any group purporting to uphold the rights of people with autism

needed parents, because the principle job of all parents is to defend and protect their children. In short, we knew that parents and professionals needed each other, if we were to make a difference in the lives of people we treasure.

We are dedicated to speaking the truth about any treatment that has shown it works, or that shows true promise, according to standards of reason and science. We really do not care if that promise comes from the biological or the behavioral realm; if autism will one day be cured by eating apricot pits and chanting poems, we will embrace that treatment – if it stands up to rigorous scientific scrutiny.

And if it does not, we will not hesitate to say so. We have seen too much time, money, and life wasted on silly fads and magic bullets, in the "try anything" approach. After fifty years of this circularity of failed treatments and faulty premises about autism, it is time to move on, to create a new vision for the future, one founded on science, and inspired by trust and compassion. For after all, none of us would be involved in this arduous task if we did not believe in three fundamental principles:

- The principle of science, by which I mean that all opinions about treatment, including ours, all hypotheses and all expertise should be challenged and tested, as we seek to identify the best possible care for people with autism.
- The principle of trust, by which I mean our assumption that people with autism are capable of learning, throughout their lives, as long as we commit to teaching them well;
- The principle of compassion, by which I mean the assumption that people with autism deserve our unfailing devotion, however far they progress or not, as cherished members of our families and our communities.

One final note: in these brief remarks, I have attempted to outline our mission and our dream. But if this mission is to thrive, it must be embraced by all of us. It is our hope that by the end of this conference, you and we will become an "us" fighting together to raise the bar and improve the lot of all children and adults with autism. For it is the children, rather than any one group, any abstract concept, theory, or scientific rule, who must inspire and unite us. As the poet Stephen Spender has said:

*"No cause is just unless it guards the innocent
As sacred trust; No truth but that
Which reckons this child's tears an argument."*

VIEWPOINT:

Applied Behavior Analysis in Speech-Language Therapy

As a Speech-Language Pathologist (SLP), my first reaction to the idea of applied behavior analysis (ABA) as a methodology with which to teach language to children with autism was discomfort. My impression was that ABA was rigidly used to teach isolated skills that are difficult to generalize, and

Applied behavior analysis has helped me to move towards becoming a more effective and accountable practitioner.

therefore did not become functional. This went directly against the grain of the training that I had received in the 1970s. At that time, open classrooms and whole language instruction were in vogue. Phonics were considered obsolete. Some educators dispersed rigid rows of desks into more relaxed clusters, and some schools did away with the walls. The objective of this informal approach to education was to encourage self-expression and creativity in both students and teachers.

In 1979, I began work at Maine Medical Center (MMC). In contrast to the more relaxed expectations of public schools, the outcome-based medical community at this teaching institution emphasized evaluating symptoms and determining diagnoses. Data-based substantiation of patients' progress and of the efficacy of specific treatment strategies was required.

In 1989, I left MMC to enter private practice. I had a particular interest in helping individuals who had little or no speech, and who would benefit from the use of Alternative and Augmentative Communication devices (AAC). In my private practice, I continued the work I had begun at MMC to develop better services for individuals in need of AAC. Referrals started coming to my practice for children with a variety of disabilities, including autism.

Teaching any non-verbal child to use AAC presents unique challenges. To begin with, AAC requires the use of symbols to

convey messages. The child has to learn to translate communicative concepts into symbols, expressively and receptively. In the beginning, this is typically taught using adult modeling of symbol use, dialogue boards, and sentence strips to "talk about" activities or items that are enjoyable for the child. Once the child has mastered the concept of symbolic language, he is introduced to the technology. This presents its own complexities.

While I had had success teaching non-verbal children who did not have autism to use AAC, teaching children with autism was much more difficult. Many of the communicative strategies on which I depended for most children were not effective for children with autism. These children did not initiate communication in the conventional ways. They were unresponsive to facial expressions or other social cues. Many children with autism have few, if any, play skills, so it was difficult to engage them. Frequently, children had little interest in playing with peers. These children with autism seemed to require far more repetition to master skills than children who did not have autism.

Regardless of the diagnoses that children presented with in my practice, by far one of the most frustrating aspects of treatment was lack of consistent follow-through in the schools, institutions, or home settings. In the case of children with autism, it was most critical that the follow-through was provided by the caregivers on a day-to-day basis. This was as important as the speech therapy that was provided for an hour twice a week. Communication strategies needed to be systematically woven into every aspect of the learner's life. This would provide the functional reason to communicate, which seems to enhance communication development for all children, regardless of disability.

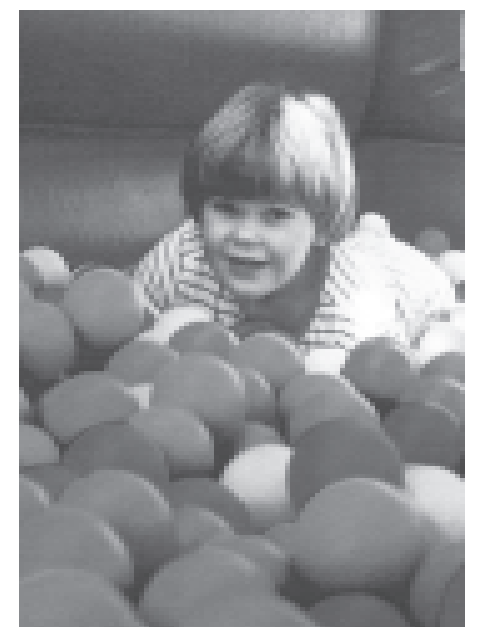
My first exposure to comprehensive ABA intervention came in 1995 with a referral to a child in a center-based ABA program. Based upon rumors and innuendo, I expected the program to be sterile. Behavior analysts teach children to be robots, I was told, and use punishment. They do nothing but discrete trials at the desk. Children are in such intensive

programs that they don't have time to be children.

After observing children at the center, I realized that these impressions were grossly misplaced. I saw that applied behavior analysis offers much to help me teach children to communicate. The staff at the center were running carefully detailed programs targeting specific communication skills one or more times each day. Despite different staff running the programs, the specificity of the steps comprising programs ensured they would be run the same way every time. Because the intervention was intensive, the learner was presented with many learning opportunities throughout the day.

And then there were the data! Staff maintained notebooks for each child, which contained programs designed to meet the learner's unique goals and objectives, and the data substantiating the child's progress. By reviewing these data, I could see exactly what level of performance I could expect from the child when I worked with him.

I also learned that the techniques used in applied behavior analysis would complement as well as supplement the strategies that I had learned to be effective in teaching com-



Natalie, daughter of ASAT Supporters Dennis and Alice Pelletier.

munication to children. Many of the techniques used during discrete trials could also be used during “teachable moments” and incidental learning opportunities. Modeling, prompting, playing, and reinforcing were tools used consistently in both ABA and speech therapy.

As time went on, I realized there can be an almost symbiotic relationship between speech therapy and applied behavior analysis. The gains children made in discrete trials prepared them to learn in more naturalistic environments during speech therapy.

From a clinical perspective, I now define goals in much more objective and measurable terms, and devise systematic hierarchies of learning based upon the child’s unique needs. Reminiscent of my Maine Medical Center days, I substantiate the efficacy of treatment with solid data. I am now much more inclined to include baseline and inter-observer agreement as I deploy new ways to teach children communication. In the beginning, this seemed to take away some of the spontaneity of my interactions with the children. As time went on, however, I learned to be spontaneous within the defined structure of the child’s program and objectives.

Furthermore, the structure inherent to ABA provides a high level of detail about the child’s learning style and rate that is useful to everyone on the intervention team. ABA also imposes an intensity and consistency that is so critical to effective speech-language therapy for many children.

Another advantage that I discovered about good ABA programs is that the staff are very well trained. Staff consistently implement programs to the letter once they are established. Staff are also very insightful when probing changes and adjustments. Initiatives to credential ABA practitioners will encourage an even higher level of professionalism, further improving outcomes for children with autism.

The requirement to collect data in ABA programs ensures that the programs are run regularly; follow-through of therapeutic recommendations is the expectation, not the exception. The SLP can establish an important partnership with ABA professionals. This partnership becomes even more important when the child is having difficulty acquiring a skill. Collaboration among professionals who know the child’s learning style well is key to breaking through obstacles to

learning.

Another advantage of having ABA staff involved in speech therapy is that these professionals already know how to do their jobs. The SLP can explain the outcome objective, and ABA staff can adjust programs or appropriately begin to fade prompts based upon analyses made possible by the emerging data.

Quite simply, applied behavior analysis has helped me to move towards becoming a more effective and accountable practitioner. I now study the ABA literature, looking for new ways to teach each and every child. I also use techniques inherent to ABA with individuals presenting with diagnoses other than autism.

But what does speech therapy bring to the discipline of applied behavior analysis? Based upon my experience, it brings much richness. SLPs can help transfer communicative skills learned in discrete trials, and other behavior analytic teaching methodologies, to the real environment. We can show behavior analysts ways to elicit communication in novel settings, perhaps by sabotaging the environment. We can offer ways to teach commenting (“the bird is blue”), or giving directives (“look at the boat!”). And we can help identify skills that the child needs in the natural environment, which may need to be broken down and taught in discrete trial or other systematic format.

At the risk of sounding psychodynamic, I’ve learned there is opportunity to “let the child lead” in speech therapy, but also to apply the methods of applied behavior analysis to lead the child back to our stated objectives.

For example, I tried to get a child to utter specific vowels and phonemes. He preferred to “speak” words using his communication device. We compromised: once the child uttered an approximation, I allowed him to also say a word with that sound in it with his “talk box.”

Another thing SLPs can bring to an autistic child’s communication plan is perspective on the *mode* of communication a child can use. Many children with autism have the cognitive ability to understand and form complex communicative concepts. Some cannot articulate these concepts verbally. We do not want to wait for a child to be verbal to teach communication, or we will hold him back developmentally and behaviorally. SLPs can offer a range of modes to augment communication, and identify the best one for the individual child.

Today when I work with teachers, aides, and families outside the ABA practitioner community, I frequently get comments such as, “He can do it if he wants to.” Now, my response is “Where’s the data?”

When I hear, “He does it most of the time,” I simply can ask, “Where’s the data?”

After a rocky start, I have become committed to the importance and value of applied behavior analysis. The data will prove it.

*Mark R. Hammond, MA, CCC-SLP
Speech-Language Pathologist
Mark R. Hammond Associates, Inc.
Portland, Maine*



Jason, son of ASAT Board Member Lora Perry and her husband Steve.

opment Consultant. Attendees were provided with in-depth information about how to develop an agency, its mission, goals and program design, as well as specifics on determining staffing needs, qualifications, recruitment and training of staff, fiscal management, public relations, fundraising, site, space and materials selection, and curriculum development. Both workshops proved extremely helpful to all in attendance.

Conference 2000: Science in Autism Treatment was a tremendous success for ASAT. We do not judge our success by how well the conference was executed, but rather by how much our attendees benefited from it. As one educator wrote, “I thank you for giving me the opportunity to learn so much in two days. As an educator in an ever-changing field, it is so essential to the children that I teach to keep up on the valuable information out there,

and you have made that possible thank you, thank you, thank you for your much needed efforts.” And finally, another educator wrote “the conference was excellent, and ASAT’s mission is amazingly on target. So much is happening to move us in the right direction – now it’s time for us to go home and use it! Where is the conference next year?” Stay tuned.

Conference tapes can be ordered by using the attached form.

Conference books containing handouts and biosketches of all presenters are available. For more information, please call the ASAT office at 516-466-4400.

PLEASE NOTE OUR NEW ADDRESS:

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ASAT

ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

THANK YOU!

Conference 2000: Science in Autism Treatment was successful due to the generous support of our sponsors, and through a tremendous volunteer effort. Sincere thanks to:

- Merrill Lynch & Co., for sponsorship of the conference manual
- Pro-Ed, Inc., for sponsorship of the conference brochure
- The Marriott Marquis Hotel, for their gracious attention to ASAT and our conference attendees
- Mike Kostel, for his support and guidance throughout the planning and implementation of the conference, and for his unwavering support of ASAT
- Bobby Newman, PhD for arranging for CEU credits for Behavior Analysts
- Andrew R. Adesman, MD, for serving as CME Course Director
- The Long Island Jewish Medical Center/Long Island Campus for the Albert Einstein College of Medicine Office of Continuing Medical Education, for their efforts with advance and onsite registration, and the administration of CME accreditation
- Melissa Andretta, Bill and Nancy Donlon, Nanette Jacobs, Anita, Bonnie and Shelly Levyns, Megan McGinn, Deborah Molloy, Ray and Diane Olsen, Marianne Simoni and Nicole Weidenbaum for volunteering their time and endless energy to the conference, and for their commitment to ASAT’s mission

ASAT would also like to thank Richard Kobel, for his assistance in the relocation of the ASAT office.

Green Receives *Psychology Today* Mental Health Award

Gina Green, PhD, BCBA, a member of the ASAT Board of Directors, is one of eight men and women selected to receive *Psychology Today*’s First Annual Mental Health Awards. The awards announced in the May/June issue of the magazine recognize “courageous people who have helped us feel and function better” through their exemplary work in mental health. Green was the winner in the category of mental health professional.

Currently the Director of Research at the New England Center for Children and Associate Scientist at the E.K. Shriver Center in Massachusetts, Dr. Green has worked with people with autism and other developmental disabilities for the better part of 20 years. She has made significant contributions to the field of behavior analysis, including serving as this year’s president of the Association for Behavior Analysis. Dr. Green has been a tireless advocate for effective, science-

based treatment for people with autism, and others with special needs.

Other *Psychology Today* honorees include David Satcher, MD, PhD, United States Surgeon General; Donald O. Clifton, PhD, Chairman, Gallup International Research and Education Center; Ann Landers, syndicated advice columnist; Judy Weber, Tobinworld Executive Director; Herbert Benson, MD, Harvard Medical School Associate Professor of Medicine; Tipper Gore, Mental Health Policy Advisor to President Clinton; and Celinda Jungheim, a survivor of mental illness.

“I’m flabbergasted but deeply honored,” Green said of the award. “It’s especially gratifying that our efforts to promote a science-based approach to autism are being recognized in a national publication. My colleagues from the New England Center, the Shriver Center, ASAT, and ABA who support and share in those efforts also share in this award.”

CONFERENCE 2000:

Science in Autism Treatment An Overwhelming Success

"As a pediatrician and parent of an autistic child, it was truly a pleasure and a welcome change to sit in the presence of so many interested, dedicated and knowledgeable professionals. My faith has been renewed. I have newfound energy to go home, to continue providing our daughter with the environment and tools for her to be happy and productive. The information I received at the conference will also be very helpful in my advocacy work for my patients, as well as in the educational and political arenas."

"What a wonderful conference! You did a tremendous job – the program was excellent, the speakers were uniformly superb, and everything went like clockwork! . . . You can enjoy a real sense of accomplishment knowing you've made an impact on the lives of hundreds of children and their families."

Conference 2000's impact on improving the lives of individuals with autism was celebrated by the over 800 attendees at ASAT's First Annual Conference on Science in Autism Treatment. Over two days in March, parents, professionals, physicians, educators and grandparents gathered at the Marriott Marquis Hotel in New York City to hear scientifically sound information about autism and treatment options from biological and behavioral experts. People came from 40 states and 8 foreign countries including Austria, Saudi Arabia, Brazil, Australia, Canada, Mexico, Puerto Rico and the United Kingdom.

The comprehensive presentations at Conference 2000 covered the most current, state-of-the-art, scientific investigation and findings on the causes and treatment of autism. Biomedical topics included Molecular Genetics of Autism, Brain Plasticity, Evidence-Based Treatments of Autism, Psychopharmacological Treatments for People with Autism, Neuroimaging Studies of Autism, and Immunogenetics. Presentations on effective, science-based treatments of autism included the topics of Brain Plasticity, Fluency, Toilet Training, Applied Behavior Analysis, Incorporating Peers, Teaching Language to Children with Autism, Naturalizing Language, Augmentative Communication, Feeding Disorders, Using Play to Learn about Objects, Events and Language in Social Contexts, and the Language, Commu-

nication and Theory of Mind Deficits In Autism.

Parents and professionals also benefited from the critical information that was presented about the early identification of autism, and the cost-benefit of behavioral vs. fad autism treatments. A highlight of the conference was an entertaining and enlightening presentation by Dr. Glenn Latham entitled Behind the Schoolhouse Door: Eight Skills Every Teacher Should Have. Dr. Latham's amusing anecdotes, extensive knowledge, wisdom, compassion, and personal experience as grandfather of a 5-year-old boy with autism touched all who heard him.

The Association for Science in Autism Treatment was pleased to honor Marie Bristol-Power, PhD, Director of the Program for Behavioral and Biobehavioral Research in Mental Retardation and Developmental Disabilities. Dr. Bristol-Power is also Coordinator of the National Institute of Child Health and Human Development/National Institute of Deafness and Other Communication Disorders (NICHD/NIDCD) Network on the Neurobiological and Genetics of Autism, and Collaborative Programs of Excellence in Autism. Before her invited address "Autism: Beginning the New Millennium," ASAT recognized Dr. Bristol-Power's tireless efforts to improve awareness of and increase research funding for autism. "Without change there can be no breakthroughs; without breakthroughs there can be no future," Gina Green, PhD said in presenting the award. "We are pleased to present Dr. Bristol-Power with this award in recognition of her lifelong commitment to science, and of her support of individuals with autism."

Attendees overwhelmingly embraced the convenience of having access to important biological and behavioral presentations under one roof. "Overall, the conference provided us with ample opportunity to increase our knowledge of autism. I was personally impressed with the highly sophisticated, documented research, reflecting the level of commitment of professionals in the field." "The two-day conference was very informative and eye opening. I learned a great deal. Excellent speakers and a great variety of topics. Thank you." "I was impressed with the highly professional nature of the conference. Well or-

ganized, knowledgeable and accomplished presenters, wide variety of interests and needs represented." "Thank you – you are helping so many families."

Continuing Medical Education Credits were sponsored by the Long Island Jewish Medical Center. Their support and recognition of the conference is greatly appreciated, and it played an important role in helping to attract more physicians to learn about autism.

ASAT would also like to gratefully acknowledge the Doug Flutie, Jr. Foundation for their support of the conference. Through a scholarship grant awarded to ASAT, 33 families of children with autism were able to attend and benefit from the conference. As one parent wrote, "This has been an incredible experience with lots of great learning opportunities. I am very thankful to the Doug Flutie, Jr. Foundation for the opportunity to be here." Another wrote, "I am so thankful that I was able to come to this conference. I am recharged to go back home and help my son with the problems he has been facing in his kindergarten class." Yet another parent wrote "What more can I say than ...WOW!! I LOVED the conference! It completely validated my program for my son, and gave me hope up the wazoo!! ASAT and the scholarship recipients wish to extend sincere thanks to the Doug Flutie, Jr. Foundation for their support of and commitment to families of individuals with autism."

The conference was complemented by two post-conference workshops. Over 100 people attended a workshop on Effective Advocacy: Protecting the Rights of Individuals with Autism given by Charles Jelley, Esq. and Richard O'Meara, Esq. Both attorneys shared valuable information about meeting the current and future needs of individuals with autism. The second workshop, How to Establish a Behaviorally Based Education Program for Individuals with Autism, was presented by the Connecticut Center for Child Development (CCCC). CCCC's Executive Director Suzanne Letso was joined by Patricia Fitzsimons, MS, CBA, Early Intervention Coordinator, and Jodi Mazaleski, MS, CBA, Elementary Education Director. Assisting the CCCC executives were Michael Solakian, CPA and Paul Grimmer, Devel-

DISTANCE-LEARNING OPPORTUNITY

The Department of Behavior Analysis at the University of North Texas (UNT) offers a distance-learning graduate course on basic behavioral principles. The course was designed by ASAT board member Dr. Sigrid Glenn, UNT Professor of Behavior Analysis. It is the first in a sequence of four courses that will cover all the content required by Behavior Analysis Certification Board (BACB) as part of their requirements for certification. The course is conducted via the Internet and CD-Rom, costs \$850, and is open to anyone with a bachelor's degree in any subject. The next course will begin in Fall, 2000. For more information, log onto the following web site: <http://webct.courses.unt.edu/public/BEHV5250SG>.

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ASAT is entirely donor supported. A single print run of this newsletter costs thousands of dollars. To date, ASAT has been able to disseminate accurate, science-based information about autism and autism treatment to all who ask, free of charge.

To continue to do that, we need your help. Please take advantage of the savings and convenience of on-line shopping at iGive.com, and designate ASAT as your preferred charity.

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Is Autism on the Rise?

From Congress to popular media, speculation is increasing that more children have autism than ever before. Call it what you'd like: autism, pervasive developmental disorder (PDD), autism spectrum disorders (ASD) or Asperger syndrome (AS). While there are clinical distinctions between these terms, they all mean the same thing to parents: "some-

Before seeking answers to these questions, it's important to understand the difference between "prevalence" and "incidence."

thing is wrong with my child." And parents want to know why.

But is it true? Are there really more kids with autism today than in generations past? Or do other factors give this *impression*? Are we just better at diagnosing children with autism? Are professionals more *willing* to make this diagnosis? Are more children referred and reported simply because more services are available? "More" children have autism relative to what?

Before seeking answers to these questions, it's important to understand the difference between "prevalence" and "incidence." *Prevalence* is the number of people at a point in time or over a period of time who have a particular identified condition. This is usually expressed as a number of people per 10,000 of the general population. *Incidence* refers to the number of people who are newly identified or acquire a condition over a period of time, often over a year or a longer period.

For example, in a population of 100,000 people, perhaps 300 have measles at any one time ("point prevalence") and 1,200 have it during the course of a year. The point (of time) prevalence is 300/100,000, and the annual (yearly) prevalence is 1,200/100,000. Assuming 300 cases at the beginning of a year, that means there are 900 new cases of measles in a year. The annual incidence rate of measles (in this purely hypothetical example) is therefore 900/100,000.

So, the prevalence of ASD can be the number of people with ASD at a point in time, and the number of new cases increases the prevalence at any point. There are other mathematical relationships between incidence and prevalence, beyond the scope of this report. Confounding things even further, the autism literature sometimes uses varied, or in-

consistent, denominators for these estimates.

An important nuance about prevalence is that its accuracy is only as good as the degree to which each individual who actually has the condition is counted (the numerator or top number of the fraction), and the completeness with which the "general" or other population has been counted (the denominator or bottom number of the fraction.) Accuracy in these two figures can be hard to achieve. In fact, there are no scientifically based epidemiological prevalence estimates for ASD in the United States at this time. Federal agencies have, however, called upon researchers to submit proposals that will develop better prevalence rates.

Until research in the United States results in more accurate figures, the National Institutes of Health (NIH) have suggested the following prevalence rates for ASD based upon research in other Westernized, developing nations:

- 10/10,000 people with "classic" autism
- 20/10,000 people with ASD, including PDD
- 50/10,000 people with ASD, including PDD and Asperger syndrome.

These estimates are inclusive; that is, the third estimate includes people in the first two groups. This means that in a given large population, on average 0.5%, one-half percent of the population, could be diagnosed with an ASD.

To put this in perspective, the best estimates of the prevalence of mental retardation is about 1.45% to 1.50%, or 145/10,000 to 150/10,000. This makes mental retardation about three times more common than autism. But the 0.5% rate for ASD is high enough to constitute a public health concern, as is the 0.2% rate for classic autism and PDD combined.

Despite the existence of these estimates, there are problems with relying upon them. First, the estimates are not from the United States, where the prevalence may be different. Second, people are diagnosed in very different ways, based on different clinical procedures, and using different diagnostic tools. There is presently no biological marker, no distinctive or particular biological signature, that serves as a benchmark for autism diagnosis. People are diagnosed at different ages and possibly by different criteria. Clinics or practitioners may use local norms; some children diagnosed according to these norms in one place or nation may not meet criteria used in another.

Numbers can be skewed because children living in some areas are more likely to be seen

by specialists than are others, and children with some health plans are more likely to have coverage for specialists than others. Specialists are more likely to practice in urban areas, but poor children, who are more common in urban areas, are less likely than are more affluent children to be seen for specialist diagnosis and treatment.

Also noteworthy is that ASD is not a group of conditions that is automatically included in public health databases. This means children with ASD often become recognized in research studies only because the child enrolls in some sort of service that does contribute to databases, or where there is other, ongoing research.

But some factors contribute to the likelihood that children with autism *will* be identified in some manner. Today, physicians and psychologists may be more informed about ASD. They may report more children more accurately, because of better diagnostic standards. Rules for diagnosis have been more specific since about 1980, and throughout the 1990s there has been increased research on Asperger Syndrome.

Consumers may have better access to professionals who can make informed diagnosis of ASDs. The numbers of developmental pediatricians and child psychologists have increased modestly, and there has been continuing federal funding through the amended Maternal and Child Health Act for institutions like children's hospitals, where these professionals work.

Heightened awareness of ASD and better practitioner skills among physicians and psychologists mean that the child who might have been diagnosed with some form of learning disability or developmental delay in the past is now more likely to be diagnosed with ASD. Screening tools and rating scales unavailable in the past help today's physicians and psychologists to better detect an ASD.

Taken individually or together, these factors do not make it more likely that children will be incorrectly diagnosed with ASD, thereby inflating the reported number of children. However, researchers are attempting to develop tools and scales that will assist even earlier diagnosis of ASD, and this might increase or decrease the prevalence of children with mild cases in the future.

However, there are at least two factors that *may* be inflating the reported numbers of children with ASD. The first is the advent of the Asperger syndrome (AS) diagnosis. Diagnostic criteria for AS require less severe problems

in living and learning than those for other ASDs. As a result, there may be some people with the very mildest apparent forms of AS who are now diagnosed but would not have

The scientific foundation for estimating the prevalence of autism among preschoolers, school age children, and adults is presently not very strong in the U.S.

been in the past, and there may be some individuals diagnosed when it is not warranted. AS diagnoses add considerably to the estimated prevalence of ASD. A good number of the AS diagnoses are made of adults, in the absence of detailed, solid information about the person's early childhood development. Questions can be raised about whether this represents sound diagnostic practice.

The second factor which may be inflating ASD prevalence is practitioners' desire to help children get needed services. After all, the purpose of diagnosis is to identify problems in specific terms that lead to well-defined, promising treatment. As scientifically based treatments for ASD are recognized, ASD diagnosis may be key to getting a child more intensive early services. These services hold the promise of significant therapeutic benefit, if the child has problems similar to those common in an ASD. This means that some children will be diagnosed with an ASD

even though they have more mild or related delays in development, or if they have behavioral problems often found in ASD. Although this practice raises some grave questions, pediatricians or psychologists may view it as a means of advocating for a child. Regardless of well-meaning intentions, this form of advocacy could inflate the rate at which ASDs are identified and reported.

The scientific foundation for estimating the prevalence of autism among preschoolers, school age children, and adults is presently not very strong in the U.S. Some may point to a 1999 report by the State of California on increased enrollments of people with ASD in Department of Developmental Services (DDS) programs (Department of Developmental Services, 1999), or the high local rate of ASD reported in a New Jersey town (Kolata, 1999), as evidence of increased numbers of children with autism. However, because of its nature, the DDS report can show only that more children are being referred and enrolled. Similarly, the New Jersey township news story may show only that the prevalence of ASD can vary greatly in small population groups, such as a particular city or town, from that of the general population. However, these limitations in no way diminish the importance of serving children and adults with ASD who have been identified and referred for services.

Until there is a "gold standard," either a biological marker or rating scale, it is hard to estimate the accuracy of the tentative NIH prevalence rates. Many of the studies on which current estimates rely were reviewed in a 1993

article by Dr. Lorna Wing. These used very different methods to identify children, and varying diagnostic criteria (Wing, 1993).

As noted before, epidemiological studies from other nations suggest it is certainly possible that the prevalence of autism has been underestimated in the past, and that PDD and AS have not been broadly and representatively studied. An apparent increase may simply be the result of better knowledge of ASDs. From the standpoint of advocacy, there are some incentives for suggesting that the prevalence of autism is increasing. However, it is very difficult to support this assertion with scientific, epidemiological evidence.

- John W. Jacobson, Ph.D.

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PLEASE HELP!

1999 was an outstanding year for ASAT. More than 40,000 copies of *Science in Autism Treatment* were distributed to parents, grandparents, teachers, psychologists, physicians, special education directors, hearing officers, attorneys, therapists, government officials, students and others, throughout the world. Our distribution continues to grow as more and more individuals touched by autism recognize *Science In Autism Treatment* as an effective tool for advocacy, and as an essential resource for science-based information on autism and treatment. The ASAT office receives requests for *Science in Autism Treatment* via phone, fax and e-mail daily. We also receive compelling testimonials from individuals directly benefiting from the newsletter's content.

Conference 2000: Science in Autism Treatment drew more than 800 people, earning praise and recognition for this premiere event. Attendees commented on the validity of the information presented, as well as its subsequent usefulness in practical application in

home, school, community and clinic settings. ASAT is overwhelmed with requests for annual conferences, and plans are already underway for next year. ASAT conferences will continue to provide state-of-the-art information on current research and best practice treatment guidelines to parents and professionals.

ASAT supported the efforts of the **Behavior Analysis Certification Board (BACB)** to ensure minimum levels of competency among ABA practitioners. To increase the labor pool of qualified ABA professionals, ASAT has been developing a graduate-level **university-based training model**, including autism-specific curriculum and supervised internship requirements for graduate programs. These initiatives will help to significantly increase the availability of qualified service providers using science-based methods to help individuals with autism.

Professionals on the Board of ASAT participate on the **National Institute of Health's Autism Coordinating Committee**, to advocate for science-based research and treatment protocols. Members of our Board of Directors have also provided testimony to **government committees**, to convey the

acute need for good, ethical, scientifically sound autism research in the behavioral and biomedical domains.

But much remains to be done. Over the next year, ASAT will continue to produce and distribute at least two issues of *Science in Autism Treatment*. The university-based training model will be piloted at carefully selected universities. Our website, currently under construction, will go online shortly, making it easier than ever to access science-based information about autism and treatment.

With your volunteer help and financial support, ASAT will continue to work tirelessly on behalf of persons with autism. Please help us to accomplish our shared vision and goal of significantly improving the lives of the individuals with autism who have touched us so deeply, and the lives of those yet to be born with this disorder.

Please give generously.
THANK YOU!