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Association for Science in Autism Treatment

SCIENCE IN AUTISM TREATMENT

Vol. 3 No. 1 Winter 2001

THE NEWSLETTER OF THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

FACING THE FUTURE WITH SERENITY

by Kathy Mannion,
ASAT Executive Director

What does the future hold for him? What kind of person will he be? What will his life and our lives be like? What kind of relationship will he share with his brother? What will he be when grows up? Will he get married, have children? These were the questions dancing in my mind as I stroked the porcelain face of my newborn son. I felt tremendous joy because he was

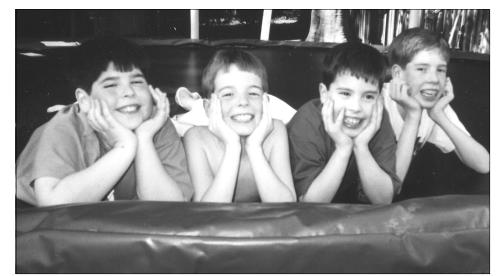
finally here, significant relief because the difficult delivery was finally over, and profound gratitude because I had a beautiful, healthy baby boy.

Eleven years later that memory is still so vivid, and the questions remain in the forefront of my mind. But anxiety has replaced the wonderment, and the reasons for my questions are so very different now.

Twenty-two months after Brian was born, I found myself posing those same questions to the social worker

handling 'our case' at an early intervention center. Brian had not developed any language. He would stare off into space for long periods of time, and he didn't respond to his name. His favorite 'toy' was a stick that he tapped incessantly on anything and everything he could find. The social worker's answers to my questions were always quite vague – in fact they weren't answers at all. Instead I got a lot of reassurance – it was still very

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Brian, Patrick, Daniel and Michael, sons of ASAT Executive Director Kathy Mannion, and her husband Tom.

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Article submissions and letters to ASAT should be sent to the above address. Submissions should include the writer's full name, address, home and work telephone numbers. Submissions may be edited for clarity or space. To order back issues, conference tapes or conference books, call ASAT at 516-466-4400.

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EDITORIAL

Science Matters

Girl Dies After Controversial Therapy was the headline of a post on Yahoo's daily news Internet site. According to the post, this "therapy" targets children who fail to form "bonds" with their parents. 10 year old Candace Newmaker of North Carolina was wrapped tightly in a blue blanket (simulating the womb). She was then surrounded by pillows with which "therapists" simulated contractions, urging the child to struggle to be "born" through a twisted "end of the blanket at the top of the girl's head." According to the report, the child told therapists 13 times she could not breathe, or was going to die. The procedure was "captured on closed circuit television. . . while the girl's horrified mother watched in a nearby room."

Somehow, "controversial" doesn't capture the essence of this tragedy. How about criminal? Outrageous? Evil? Where are our minds? How can this be happening?

We are so desperate, and therefore so vulnerable to quackery.

Make no mistake about it: there are consequences of "new age," "alternative," antiscience "options" that proliferate around autism and other disorders. It starts out innocently enough—how can a soft blue blanket, a bunch of pillows and some noted practitioners be a prescription for a child's last breath?

It was for Candace. . .

For every child who dies in such "controversial" therapy, how many have been injured? How much of our precious time and limited resources are squandered?

This tragedy illustrates the importance of ASAT's commitment to provide accurate, science-based information, and to promote access to effective treatment. As parents, professionals and advocates, we need to provoke the consciousness of those who propose interventions for our children with one overriding value: science *does* matter.

- Lora Perry, Editor

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.

SAVE THE DATE

CONFERENCE 2005

March 8-10, 2001
Second Annual Conference
On Science in Autism Treatment
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INCREASING SOCIAL LANGUAGE • FLUENCY-BASED INSTRUCTION
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For more information or to request a conference brochure contact ASAT 516-466-4400 by phone or ASAT@autism-treatment.org by email

Framework for the Future:
Creating a System to Develop Effective
Treatment Practitioners for the New Millennium
SIGRID S. GLENN, Ph.D., BCBA
SHAHLA ALA'I-ROSALES, Ph.D., BCBA 20-ASAT-19

Behavorial Assessment and Empirically
Supported Treatment of Feeding Disorders
in Children with Autism
WILLIAM H. AHEARN, Psy.D. 20-ASAT-20

Incorporating Peers in the Treatment of Children with Autism: Putting Research into Practice - Part II BRIDGET A. TAYLOR, Psy.D.

20-ASAT-21

20-ASAT-22

Immunogenetics: Hopes and Cautions WILLIAM M. McMAHON, M.D..

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early, Brian was still very young, there was a lot to hope for and, of course, we "were not alone."

As a mother, stripped of her ability to help her children and robbed of their love and affection, I felt so helpless, and life seemed so hopeless.

I remember attending a parent support meeting and asking for more concrete information. I expressed my need to know what we were dealing with and what might be in store for the future. "Why do you want to know?" asked one parent. "I don't think I could handle knowing," said another mother. "I don't want to know," proclaimed another, "that way I can always hope for the best." "But that's exactly why I need to know" I replied, "so I can learn about Brian's needs and do everything I can to ensure that they are being met." That is what would give me peace of mind, that is what would allow me to be hopeful.

A little more than a year later, as I completed the forms to admit Daniel, Brian's younger brother, to the same early intervention program, it was difficult to have hope, and impossible, I believed, to ever again have peace of mind. By now all four of my children had been born. Michael, the oldest, was just 5 years old. Brian, now almost 3 and a half, had made little, if any, progress. Daniel was barely two years old, and had spent the past year tantruming all day and

walking the halls each and every night. And Patrick, the baby, was just 8 months old.

The days were long and the nights

were endless. The behaviors got worse, the problems got bigger, the needs became more substantial, and the demands on my time were endless. Life became too painful to witness, too exhausting to endure and, seemingly, too difficult to survive. More than anything, I wanted to escape and run away from all of it. It was so hard to watch the children struggle, and so difficult to find any effective way to help them. I couldn't wait for each day to end, but hated to see nighttime come because it meant that another day would soon begin. As a mother, stripped of her ability to help her children and robbed of their love and affection, I felt so helpless, and life seemed so hopeless.

I hoped that the passage of time would bring improvement. I was wrong. A simple trip to the grocery store with the children took all the courage I could muster. Typical family outings to the park, the library or a friend's house were virtually impos-

sible. Visits to the pediatrician's office became a nightmare, and our house was in a state of unending chaos. There was very little to enjoy, and so much to be concerned about. We were imprisoned in our own home – able to do less and less – as our world became smaller and smaller. I watched other families from afar

enjoying family life, and I wondered if we ever would. We had a house full of children, yet there was very little childhood there.

The concrete information I was longing for arrived three years later. Brian and Daniel had autism. Finally we had a diagnosis and, hopefully, we would get some direction. Not so. Diagnosis: autism. Cause: unknown.

We had a house full of children, yet there was very little childhood there.

Life expectancy: normal. Prognosis: grave. With that news came a strong recommendation for me to join a support group, a cheerful reminder to take time for myself, a list of schools willing to 'take' kids like Brian and Daniel, and a word of caution not to forget that I had two 'other' children, and to always remember that they had needs too.

As a child, I had been gleefully unaware of my own mortality. When I

continued on next page



Brian and Michael Mannion

ASAT

FACING THE FUTURE WITH SERENITY

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became a mother, I grew much more cognizant of it. As the mother of two children with profound deficits and needs, I became haunted by it. What will happen to Brian and Daniel when I'm no longer here? Where will they live? Who will take care of them? Who will love them, understand them, meet their needs, have patience with them, and ensure their welfare? And what about Michael and Patrick? How will autism effect them and their lives? The questions are still quite painful, but the answers have become a little clearer.

I knew that the only way I could have peace of mind was to do everything I could to make sure that the needs of all four of the children were met. I wanted each of them to be able to maximize their full, God-given potential – whatever that might be and I wanted each of them to live a decent life, filled with love, security, dignity and inner peace. My motivation to provide this security was twofold: the desire to give them the opportunity to grow to be the best they could be, and the desire to ease the burden on each of them when Tom and I were no longer there to take care of them.

Although I'd like to say that I was equally motivated by both goals, the latter consumed me. Michael, at the tender age of 7, had already witnessed and lived with more stress and uncertainty than most people three times his age. It was also obvious to us, from watching his patient and loving way with his brothers, and the

(4)

wisdom, compassion and maturity he displayed far beyond his years, that Michael would be drawn to become their caretaker when the time came.

Although Michael's devotion made me extremely proud, it brought more anxiety than comfort. I wanted to

Years of prayers and investigation did not lead us to a cure. It did, however, lead us to a science.

make sure that this would be a free choice for Michael to make, not a mandate proclaimed by an assumption on our part. I also felt compelled to do everything we could to leave Michael and his brothers with as little difficulty to deal with and live with as possible. I knew how hard it was to be a caretaker, how exhausted I was, how overwhelmed I often felt, how frustrating it could get, and how draining it could be. I also saw how hard it was for Brian and Daniel to do even the simplest of things, how frustrated they would get, how overwhelmed with the world they often seemed and how much help they needed. There was so much to be done, and not a moment to waste.

I concluded that the only way I would ever be able to die in peace was to ensure that everyone's needs were being met, and by working as hard as I could to ease everyone's burden.

I set out to find out everything I could about autism and its treatment. I began to pray that things would change, that the autism would disappear, that it would all be just a bad dream and that we would find a cure.

As a child, I was taught that God hears and answers every prayer, although sometimes His answers differ from what you request.

Years of prayers and investigation did not lead us to a cure. It did, however, lead us to science.

We didn't recognize it at first, but Applied Behavior Analysis became the answer to our prayers. It took some time for us to embrace it. At first glance it seemed rigid and cold rather than warm and nurturing, but we were drawn to the data that supported it, particularly since we had spent the last three years in ineffective intervention programs. The more we learned, the more we liked. Once Brian and Daniel started receiving effective intervention and Tom and I began receiving effective training, our lives began to slowly improve.

We learned how to be proactive rather than reactive, to anticipate situations and to analyze behaviors. We learned to seize teaching opportunities, and to catch good behavior and deliver lots of praise. We learned how important it is to be consistent; in-

Inconsistency on our part was actually teaching persistence on their part.

consistency on our part was actually teaching persistence on their part. Above all, we learned that Brian and Daniel could learn and that through hard work, consistency and determination, our lives could and would improve. We were no longer alone or helpless and, finally, there was reason

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Were You Unable to Attend Conference 2000? Do You Wish You Could Hear It All Again?

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20-ASAT-12

THURSDAY - MARCH 9, 2000

WELCOME - Richard Foxx, Ph.D. & INTRODUCTION TO ASAT - Catherine Maurice, Ph.D., President

Molecular Genetics of Autism JOSEPH D. BUXBAUM, Ph.D.

20-ASAT-01

FEATURED SYMPOSIUM ON BRAIN PLASTICITY:

MAXIMIZING HUMAN POTENTIAL THROUGH

EFFECTIVE AND APPLIED

LEARNING TECHNIQUES - PART I

Does Behavioral Intervention Change the Brain?

GINA GREEN, Ph.D., BCBA

Antagonizing Brain Damage in Adulthood by Learning

RICK TESSEL, Ph.D. 20-ASAT-02

GENERAL SESSION:
FEATURED SYMPOSIUM - PART II
The Quality and Quantity of Experience
Needed for Brain Development:
Some Lessons From Animal Research
JAMES BLACK, M.D., Ph.D.

Reorganization of Brain Functioning through Learning and Practice GEORGE NIEMANN, Ph.D.

20-ASAT-04

20-ASAT-03

Clinical Practice Guidelines:
Methodology, Findings and Implications
STEPHEN R. ANDERSON, Ph.D. 20-ASAT-05

Project Play: Using Play to Learn About Objects,
Events and Language in Social Contexts
KARIN LIFTER, Ph.D. 20-ASAT-06

Fluency-Based Instruction:
A New Standard for Teaching Effectiveness
CARL BINDER, Ph.D. 20-ASAT-07

Teaching Language to Children with Autism:
Scientific Foundations of Behavioral Language
Assessment and Intervention
JAMES W. PARTINGTON, Ph.D. 20-ASAT-08

Cost-Benefit of Behavioral and Fad Treatments for Autism Spectrum Disorders: What Have You Got to Lose? JOHN W. JACOBSON, Ph.D., BCBA

JAMES A. MULICK, Ph.D. 20-ASAT-09

Applied Behavior Analysis: The Critical Need for Focus on Analysis, Not Technique RAYMOND G. ROMANCZYK, Ph.D.

Defining the Language, Communication

and Theory of Mind Deficits in Autism
HELEN TAGER-FLUSBERG, Ph.D. 20-ASAT-11

FRIDAY - MARCH 10, 2000

GENERAL SESSION: Behind the Schoolhouse Door: Eight Skills Every Teacher Should Have

GLENN I. LATHAM, Ph.D.

Early Identification of Autism

DEBORAH FEIN, Ph.D. 20-ASAT-13

Naturalizing Language:
A Critical Review of Speech/Language
Research and its Implications
for Treatment Within a Behavioral Model
JOANNE E. GERENSER, MA, CCC-SLP 20-ASAT-14

The Social Brain: Building a Model

From Neuroimaging Studies of Autism 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 REICHLE, Ph.D. 20-ASAT-17

Incorporating Peers in the Treatment of Children with Autism: Putting Research into Practice - Part I

BRIDGET A. TAYLOR, Psy.D. 20-ASAT-18

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SCIENCE IN AUTISM TREATMENT **WINTER 2001** SCIENCE IN AUTISM TREATMENT **WINTER 2001**

MEETING THE NEEDS

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sufficiency. According to Individualized Resource Planning (1995) "Wraparound is based on individualized, needs-driven planning and services. It is not a program or a type of service. It is a value base, and an unconditional commitment to create services on a "one kid at a time" basis to support normalized and inclusive options for youth with complex needs, and their families."

These "normalized and inclusive options" can be defined by the wraparound team to ensure the safety of our children. For example, the team might decide safety can be achieved through increased staffing for the child in the home and community, supplemented by the purchase of security technology including fencing, door alarms and tracking devices. The requirement to utilize methods of treatment and education that are scientifically validated as effective based upon peer reviewed science can also be included in the wraparound, individualized service plan (ISP).

Of course, the best planned and funded services for our children are of no use without the human resources necessary to implement them. At a time when unemployment flutters between 3 and 5%, this is a significant challenge that must be identified by the wraparound team and systematically overcome, "one kid at a time."

By "human resources," we don't mean simply people who pass the "foggy mirror" test (translation: if they're breathing, hire them.) The wraparound team needs to build

strong foundations for our children that will protect their safety and nurture their independence throughout their lifetimes; therefore, wraparound teams must assume the responsibility of investing in the professional development of a work force which can use scientifically validated treatment, care and education methods, "one

BEHAVIOR ANALYST CERTIFICATION BOARD UPDATE by Gerald L. Shook, PhD, BCBA,

BACB Executive Director, ASAT Board Member

The Behavior Analyst Certification Board (BACB) currently has over 450 certificants in 27 states and the UK. This includes individuals who have transferred their state certification to the BACB. There will be administrations at various sites nationally on May 19, 2001, and one on May 30, 2001, which will coincide with the Association for Behavior Analysis Annual Convention in New Orleans. Application deadline for these May administrations are March 5, 2001.

Individuals who are interested in arranging to have the examinations administered in their area should contact the BACB Executive Director. Information on future administrations and applications are available on the BACB website.

Individuals applying to become a Board Certified Behavior Analyst (BCBA) or Board Certified Associate Behavior Analyst (BCABA) must meet degree, coursework and experience requirements to be eligible to take the certification examinations. Three options to the BCBA coursework requirement are available, on a time-limited basis, for applicants who may not be able to document the required coursework but who have engaged in approved alternative behavior analytic activities.

State certificants must transfer to

BACB Certification by June 30, 2001. The BACB website, www.BACB.

com, has been expanded to include an examination results summary, information on the examinations and administration procedures, Frequently Asked Questions for applicants, Continuing Education Units information, renewal and draft recertification applications, an improved application download capability, and updates of existing pages. The website contains a new Certificant Registry that lists the name, city, state and certification level for active BACB certificants. The BACB website is the best source for current information on all aspects of the BACB and its activities.

The Association for Behavior Analysis will approve Continuing Education Units required to maintain BACB certification. An ABA committee, chaired by Dr. Gina Green, is developing approval policies and procedures. Committee members include representatives from state affiliated chapters, the chair of the ABA Affiliated Chapters Board, ABA and the BACB.

The BACB is developing an approval process for university curricula that meet the coursework requirements for taking the examinations. Individuals who are interested in having their curricula approved by the BACB should check the BACB website. •

DISTANCE-LEARNING

The Department of Behavior Analysis at the University of North Texas (UNT) offers a distance-learning graduate internet course on basic behavioral principles three semesters a year (BEHV5250). This course is a prerequisite to three more on-line courses that, together, cover all of the content required by the Behavior Analysis Certification Board (BACB) as part of their requirements for certification. The course is open to anyone with a bachelor's degree in any subject. Registration deadlines are December 15, 2000, April 15, 2001 and August 1, 2001. The cost is \$900, plus text and CD-Rom.

The next graduate course in the series, covering behavior analytic principles and methods in applied settings, will be offered in Fall 2001. Registration deadline is August 1, 2001.

UNT also offers an undergraduate internet course, Behavior Principles I (BEHV2300). Registration deadlines are December 15, 2000 and August 1, 2001. The cost is \$600, plus text and CD-Rom.

Fees for both courses for Texas residents are set by UNT and are listed in the catalog at http://www.unt.edu/ catalogs/2000-01/.

The course was designed by ASAT board member Dr. Sigrid Glenn, UNT Professor of Behavior Analy-

For more information, visit http:// /webct.courses.unt.edu/public/ BEHV5250SG & http://webct. courses.unt.edu/public/ BEHV2300SG. ◆

APA APPROVES NEW SPECIALTY

by John Jacobson, PhD, BCBA, ASAT Board Member

The APA has approved the specialty in behavioral psychology for graduate training, passed in its entirety but not by acclamation, on August 3, 2000 in the APA Council of Representatives. This becomes the 9th specialty.

The effort to obtain approval was spearheaded by James Mulick of Div 33 and David Eckerman of Div 25. There was vocal and effective support from the Division of Experimental Psychology and the Division of Psychoanalysis, and by Peter Nathan. Numerous state representatives encouraged deferral of the specialty, that

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seemed to them to overlap too much with their existing specialties. The argument was essentially that they were all behaviorists too.

The outcome was uncertain until the vote was taken. Interested universities have seven years to complete the process of starting a program, as do internship sites. The process of approval for departments to apply will often require as long as two years from inception of the effort. Self-study packets should be available by request to the APA Education Directorate (see www.apa.org). •

YOU CAN FIND US ON THE WEB www.asatonline.org

professional at a time." This means

including training costs in a wrap-

around budget, as well as wages suf-

ficient to attract and retain already

With committed planning and co-

ordination, we can support the whole

child; and, perhaps, we can even re-

capture a certain stability of life that

diminished or disappeared when the

diagnosis of autism entered our

Vandenberg, J., Donner, R.,

Grealish, M., Miles, P. Stieper, C.,

Franz, J., Brown, N., Lubrecht, J.,

Huff, B., Reed, C. (1995). Indi-

vidualized resource planning:

Wraparound training. Maine: De-

partment of Mental Health and

Mental Retardation Bureau of Chil-

dren with Special Needs.

lives. •

REFERENCE:

qualified staff and supervision.

ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

ASAT

BOOK REVIEW

WHEN EVERYBODY CARES: CASE STUDIES OF ABA WITH PEOPLE WITH AUTISM

By Bobby Newman, Ph.D, B.C.B.A.

Published by Dove and Orca, 1999

Available from Bookmasters, 800 247-6553 or from www.difflearn.com

by Catherine Maurice
January 2001

The popular stereotype of the behavior analyst is that of the cold intellectual who is interested only in controlling others...Everyone...would prefer that the behavior analyst would just stay in his or her coffin until a student is throwing furniture through the window. When all else has failed, reluctantly, someone knocks on the coffin and the behavior analyst rises up like Dracula to supply a behavior treatment plan. Having served his or her purpose, the behavior analyst returns to his or her coffin until called on again. (p.112)

With humor, honesty and a good deal of caring, Dr. Bobby Newman, Director of Training at the Association in Manhattan for Autistic Children, Inc., takes the reader through a score of "case studies" - illustrative vignettes about the children and adults he has worked with over the years. Case studies, of course, do not constitute experimental or controlled research, and the field of autism intervention has suffered because both the providers and the recipients of many such intervention services have often muddled the two classes of information. (How many "case studies" abound about the effectiveness of bogus treatments?) But Dr. Newman's work does not fall into this trap. He clearly presents these real-life stories as examples, each exploring how a principle of behavior analysis (a field that *has* produced over five hundred controlled studies), or an aspect of autism happened to play out in the case of particular individuals, in particular times, places and fami-

Dr. Newman truly cares about these kids, and most likely you will, too. Newman appears to assume throughout his discussions that parents are intelligent and loving – a welcome assumption, set against the historical tendency of many professionals to portray parents as incompetent, uncaring, or just plain dumb.

lies. He encourages readers to draw what they can from these case histories, while emphasizing a guiding principle of any behavioral approach: Each child is different. Each program must, of necessity, be tailored to each individual child. Thus we can read about real children and young adults who may have struggled with perseveration, obsessions, direction-

following, appropriate greetings, selfinjury, lack of play skills, social avoidance, self-care, appropriate conversational skills, and the like, and learn about the trial and error approach that eventually helped these individuals to achieve a greater degree of selfmanagement and independence.

What I find particularly appealing about this little book is not only the "real-life" aspect of the stories (Dr. Newman truly cares about these kids, and most likely you will, too), but the author's often self-deprecating humor, his willingness to share his pride, joy, frustration and mistakes, warts and all. I also appreciate his attitude toward parents: he appears to assume throughout his discussions that parents are intelligent and loving - a welcome assumption, set against the historical tendency of many professionals to portray parents as incompetent, uncaring, or just plain dumb.

Are there any non-success stories? Frankly, no, but of course, that brings up the question of what constitutes "success." Newman is careful to do two things: One, to actually admit the reality of recovery, a word that gets certain members of the old guard into a sputtering rage ("Impossible! Never never never!"). Two, to emphasize that even where recovery has not occurred and may never occur, these children and young adults do

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MEETING THE NEEDS OF THE WHOLE CHILD

by Lora Perry, MS, ASAT Board Member

I am aware of five children with autism who have died tragically in the last year: three died in fire, and two drowned after slipping out of the home unnoticed.

These tragedies touch us all deeply—not only because of the searing empathy we feel for these grieving families, but also because they remind us with chilling clarity of the vulnerability of each child with autism.

In addition to our abiding and nurturing love, children with autism require care, treatment and education. The absence of any one of these puts our children at high levels of risk. It is our job as parents and advocates to educate legislators, schools, funding authorities, service providers, gatekeepers and ourselves about the non-negotiable importance of a plan and resources to protect the whole child.

Care includes ensuring the child is properly nourished. The child must have access to routine and targeted health and dental care delivered by professionals, and daily in the home. The child must be bathed daily, benefit from adequate sleep, and be protected from the dangers of wandering, traffic, drowning, fire, exploitation, and other home and community hazards.

Treatment is calculated to maximize the child's potential for a self sufficient and rewarding life. Treatment objectives therefore include daily living skills, communication, "learning to learn," and interventions targeted

to overcome interfering behaviors including incontinence, self injury, aggression and significant property damage.

Education is delivered to help a child achieve or make progress toward specific academic goals. In many cases the individualized educational plan for

Wraparound models have the potential to raise the bar for our children academically, keep them safe, and steer them toward lives of self sufficiency.

children with special needs includes treatment goals. However, under the Individuals with Disabilities Education Act (IDEA), public schools are not obligated to ensure that children maximize their potential in any domain; rather, schools must allocate sufficient resources in terms of method, frequency and intensity to document progress toward defined goals. Furthermore, and while we are quite fortunate to have this entitlement, IDEA's mandate places a potential "cap" on the child that will have implications over a lifetime. Outcomes can be predictably less than optimum.

Consequently, to achieve outcome objectives important over the child's lifetime, school services must be supplemented.

Increasingly, parents, educators, health care providers and legislators are looking for ways to more equitably dis-

tribute the responsibility for a full range of services calculated to help children with special needs achieve outcome objectives for more self sufficient lives. Such evolving models go by different names, among them "blended funding" or "wraparound services."

Traditionally, services for children with special needs have funneled toward existing programs and resources. This sort of "predetermination of placement" is not even IDEAcompliant. IDEA requires that a Pupil Evaluation Team (PET) define specific academic goals and objectives for the child before proposing the method, frequency and intensity of services required to help the child achieve those objectives. "[T]he appropriate placement . . . cannot be determined until after decisions have been made about the child's needs and the services that the public agency will provide to meet those needs. . . . Therefore, the IEP must be developed before placement. (Further, the child's placement must be based, among other factors, on the child's IEP)." 34 C.F.R. Part 300, Appendix A, 64 Fed. Reg. 12406, 12475 (March 12, 1999). However, this legally-mandated process is frequently disregarded for the sake of expediency, or because educators are insufficiently informed.

Wraparound models have the potential to raise the bar for our children academically, keep them safe, and steer them toward lives of self

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FACING THE FUTURE WITH SERENITY

continued from page 4

for hope.

Six years have passed. Many things have changed, but some remain the same. Although we still and

Parents of special children learn to perceive the ordinary as miraculous.

always will have a significant amount of work ahead of us, our family enjoys many of the things we were once denied. Saturday nights usually find us enjoying dinner at a local restaurant, something that brings shared delight to all of us. We enjoy family vacations, long car rides, trips to the mall, outings to the park, the movies, and yes, even the grocery store. I have no hesitation taking the four children anywhere by myself, something I could never do years ago.

A friend once said that "parents of special children learn to perceive the ordinary as miraculous," and I have found this to be profoundly true. I have come to deeply appreciate the 'ordinary miracles' in our daily lives. My telephone conversations are often interrupted by children eager to tell or ask me something. Although I pretend to be upset when they argue, I will be forever grateful for the sibling rivalry that has developed. My stern voice insisting "get to sleep, up there" doesn't reflect the joy I feel listening to their simple, late-night conversations. And after years of complete disinterest, the children's nagging for a new toy every time we enter a store is most welcome. You come to appreciate such things that much more, when you have been deprived of them for so long.

These changes in the children and in our lives did not come quickly or easily; perhaps that is why they are so cherished and meaningful.

What remains the same? Michael does. And so does my desire to die in peace. I still pray every day for a cure, but I also ask for serenity. I pray for "the ability to accept the things I cannot change, to change the things I can, and the wisdom to know the difference."

In a recent essay Michael, now almost 14, wrote that the person he admires most in history is Helen Keller, because she not only overcame her own struggles, she went on to help others facing similar struggles. He said that he would consider it a huge accomplishment if he could go on to help people less fortunate than him in his lifetime.

We were right about Michael and his aspirations, and we were right about behavior analysis and the 'serenity' that it brings us. Because of both of them, I know that my prayers have been answered. Because of both, I know now that someday, I will die in peace. •

HELP DESK

continued from previous page

very, very persistently repeated response prevention. The are many possible variations on this general intervention strategy, but the keys to suc-

cess, as with any behavioral intervention, are in persistence, immediacy, and in the availability of other things to do and other ways to obtain similar stimulation in acceptable ways. Care should be taken, obviously, *not* to offer an "acceptable" way to obtain oral or nutritional stimulation immediately after an attempt to bring non-food material to the mouth, because this would actually reinforce an instance of pica.

It may also be possible to teach a discrimination based on visual cues, such that the child learns to taste and eat only those things obtained from a brightly colored plate, for example, or from a formal place setting on a distinctive tablecloth. Sometimes children must be actively discouraged from going after certain dangerous

There is no substitute for protective measures.

objects that represent a marked health risk if swallowed. Such treatment requires a carefully designed, professionally supervised and conscientiously delivered behavior program. The program details for any youngster must be individualized. The necessary teaching resources and people to be involved need to be arranged advance. Again, these measures should not be undertaken lightly or sporadically, because there is a risk from inconsistent implementation that the child could learn to be more secretive about pica, and not actually decrease this dangerous behavior. •

FREELOTTO & ASAT ARE A WINNING COMBINATION!

Thank you to FreeLotto.com, a free Internet lottery/ sweepstakes site owned by Plasma-Net, Inc., for selecting ASAT as a participant in their FreeLotto Charity Program.

FreeLotto is the 9th largest site in the world as measured by page views, and currently has over

10.5 million players worldwide. Each month FreeLotto sends over 200,000 prize checks, most of which are \$1 and \$5 checks. With the launch of FreeLotto's new Charity Program, the winners of these



prizes are sent an e-mail giving them a choice of receiving their prize check, or clicking on a link to donate the prize amount to one of 25 pre-selected, leading charity organizations.

The Charity Program, which was

launched in August, has been a huge success. In addition to bringing much needed programmatic funds to ASAT, the program has helped to increase awareness about autism and ASAT among a constituency of enormous size. ASAT is grateful to FreeLotto and PlasmaNet, Inc.

for their tremendous support and commitment.

You can play FreeLotto every day at www.freelotto.com – there's nothing to lose, and so much to win! •

BOOK REVIEWWHEN EVERYBODY CARES:

achieve significant success, if success is defined as step by step progress towards independence; as maximum possible integration into a social community; as an ability to communicate one's wants, needs, and desires. In each of these case studies, the child or teenager inspires us with hope, because even while the road is long, and there may be many hurdles yet to overcome, we see these young ones mastering particular challenges, one at a time, and we rejoice for them.

Problems? Maybe a few, non-essential. The author tries to speak in

plain English, translating that ponderous behavioral jargon as best he can, and for the most part, he succeeds. This work can actually function as a neat little primer on some basic behavioral principles. On more than one occasion, however, the text cries out for a higher degree of professional editing than it may have received. At times, the syntax is convoluted, the grammar flat out wrong, ("who" for "whom," "lay" for "lie," etc.) and the meaning murky. "The commodities from the menu, it turned out, did not occasion inappropriate behavior the way the reinforcers that the staff had selected, including verbal praise, had." (p.47) Sometimes, the text is too wordy, sometimes a bit too

elliptical. For instance, we are told to use "telegraphic speech" at the beginning of a child's learning, but Dr. Newman does not go into any rationale for this recommendation. Since the anti ABA folks just love to jump on telegraphic speech as an example of how cold and mechanical behavior analysts are, it may have been wise to include a sentence or two of explanation here. But never mind. For what I think this text can bring to anyone who cares about people with autism, these decoding challenges are a small price to pay. I would have drawn much hope and help from this book, had it been available to me when my children were in treatment. •

SCIENCE IN AUTISM TREATMENT **WINTER 2001 WINTER 2001** SCIENCE IN AUTISM TREATMENT

PLEASE GIVE GENEROUSLY

Dear Friend,

Accurate information. Access to effective treatment. Hope for our sons' future our family's future. Little enough to ask for, we thought, in the wake of hearing that our two year old twin sons, Jason and Joshua, have autism. But to our dismay, we discovered we were on our own.

That's why I want to ask you for a very special annual contribution to the Association for Science in Autism Treatment (ASAT). What happened to our family, and to so many others, should never happen

MISINFORMATION

I ran to the bookstore to learn more about autism. Book after book consigned my sons to a life of aloneness, void of imagination, language and love. Autism would rob my sons of friends, school, a profession, marriage, parenthood—it would rob richness from precious lives that had barely started.

Today, I know these prognoses were overly grim.

We faced a dizzying array of treatment choices, each accompanied by passionate proclamations of effectiveness. How could we choose? Which intervention offered our sons their best hope for a life as full as possible? Were all options equal?

When you contribute to ASAT, you help increase the likelihood that families like yours and mine will have timely access to clear, accurate, science-based information about autism and treatments information that helps us identify the fads, philosophies and "miracle cures" that have plagued autism intervention for decades.

WASTED TIME

We searched internet sites and met with early intervention providers, as each day we watched our sons withdrawing more and more into autism. We needed to do something right away! Surely there is no more painful experience for any parent or grandparent than to helplessly watch a child who is there, but not there; one who speaks, but cannot express thoughts; a child who looks, but will not engage with what he sees; a child to whom the birthright to love, and to accept love, is denied.

UNQUALIFIED PROFESSIONALS

State officials arranged meetings with "autism specialists" for us, but we discovered that these professionals had no clinical or academic qualifications in the treatment of autism; rather, they were administrators responsible for pairing families with existing resources, whether these interventions were effective for autism or not.

When you contribute to ASAT, you help us with outreach to educate case managers, special educators, physicians, Medicaid, private health insurance carriers and autism intervention practitioners. ASAT strives to teach these professionals how important it is to invest precious resources in autism treatment and education that is scientifically validated as effective.

PSEUDOSCIENCE

Finally, our family realized that it was somehow up to us to figure out what science had proven to be effective for individuals with autism. We needed to learn how to distinguish between rigorous, sound science, and pseudoscience—"information" presented in a format calculated to infuse beliefs, speculations, and untested assumptions with credibility, despite the lack of objective, peer-reviewed evi-

When you contribute to ASAT, you help us to continue to offer yearly conferences at which the most respected science professionals present state-of-the art autism treatment, education and research—information that can improve the quality of the lives of the people we love today.

LEGAL ACTION

Our family's requirement for scientifically validated intervention met with vigorous resistance by public officials who were the "gatekeepers" of early intervention. At great personal financial and emotional expense, we hired an attorney and filed for due process. Not long after, our case was settled. Finally, we could get on with the business of helping our children.

NOT ENOUGH PRACTITIONERS

Or could we? Professionals experienced in scientifically validated autism treatment methods were far and few between. And there was no way to validate the credentials of practitioners who claimed to be qualified to do this work. Our practitioners were honorable and hard working, but nevertheless insufficiently educated and experienced.

Your contribution to ASAT helps us to continue to support the efforts of the Behavior Analyst Certification Board (BACB), to ensure minimum levels of competency among ABA practitioners. Your support also helps ASAT to develop a more adequate labor pool of qualified professionals, through our continued work on a graduate-level university-based training model, including autism-specific curriculum and supervised internships.

TODAY

Today Jason and Joshua are seven years old. They receive treatment and education comprised entirely of scientifically validated methodologies, delivered and supervised by appropriately credentialed professionals. I wish I could say similar intervention integrity is likely for the families who are receiving a diagnosis of autism for their son or daughter today, but I cannot. Even today, much responsibility remains imposed upon parents and professionals to wade through the quagmire of misinformation. Families are still likely to access services controlled by unqualified gatekeepers and practitioners, and to endure life-draining conflict over "what works" and what does not work in the treatment of autism.

That's why ASAT needs your financial, tax deductible help.

Please support ASAT as generously as you can by using the attached reply envelope. Your contribution will help us to continue our mission to disseminate accurate, scientifically sound information about autism and treatments for autism, and to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

Imagine a world in which every family faced with a diagnosis of autism enters a service system that is familyfriendly, science-based, and outcome driven. With your generous financial support, ASAT will continue to bring us closer to that goal.

Thank you!

Sincerely

Lora Perry Lora Perry, MS

Science in Autism Treatment

Please give generously. THANK YOU!

DO YOU KNOW SOMEONE WHO WOULD BENEFIT FROM RECEIVING SCIENCE IN AUTISM TREATMENT?

Parents, pediatricians, psychologists, educators, social workers, legislators, service providers, grandparents, speech pathologists, psychiatrists, researchers, advocates and others rely on the thoughtful, well reasoned information contained in the ASAT newsletter.

Send us the names and addresses of individuals to add to our mail list by mail, Association for Science in Autism Treatment, 175 Great Neck Road, Suite 406, Great Neck, NY 11021; by phone: 516-466-4400: by fax: 516-466-4484; or by e-mail: ASAT@autism-treatment.org. ASAT is happy to distribute Science in Autism Treatment free of charge.



HELP DESK

nately, the modern world is not free of danger. Some danger is not readily apparent to children or their parents until it is too late. Lead, mercury, and ionizing radiation, for example, are toxic in very small quantities, and can have increasingly deleterious effects as exposure accumulates over time. Lead actually tastes slightly sweet, and a blob of mercury has just that moderate amount of visual change to be endlessly fascinating to a young child. Radioactivity is imperceptible. Other toxic or dangerous substances are insufficiently foul or painful to rapidly teach an alert child to avoid them without adult intervention. It is a dangerous world.

Most children learn to avoid most hazards. They escape poisoning and injuries as a result of parental protection until they know better. Toddlers are most susceptible to harm from pica, with lead poisoning from leadbased paint dust in old housing peaking at those ages when toddlers are

ambulatory, but still explore everything with their mouths and eat finger foods from unwashed hands.

Some young children fail to learn to avoid toxic and other dangerous

The keys to success, as with any behavioral intervention, are in persistence, immediacy, and in the availability of other things to do and other ways to obtain similar stimulation in acceptable ways.

substances. This can be a result of failing to teach children appropriate caution, especially for things that neither look nor taste dangerous to the children. However, it is more likely to represent impaired sensation or a profound learning disability when it persists in the older child. After all, pica is merely the reflection of fundamental nutrition-seeking behavioral tendencies which serve an adaptive function in all children. It is a

dangerous behavior because poisons are not always signaled in ways that produce aversion or fear until they are followed by illness or pain. Sometimes this happens too quickly, or it can happen so much later or so gradually that there is no direct association for the child, despite biological preparedness in all healthy people to learn such things quite rapidly.

When children do not learn to avoid ingesting poisonous or dangerous substances they can reach, there is no substitute for protective measures. The home should be thoroughly 'child-proofed' so that toxic or sharp items are kept securely out of the reach of the child with pica. Toddlers and children who are excessively fascinated by tastes and smells and who cannot be readily taught to avoid such dangers must be closely supervised while they are awake and freely mobile.

Some children can learn to avoid attractive but hazardous tastes by

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HELP DESK

by James Mulick, PhD
ASAT Board Member

Science in Autism Treatment is pleased to introduce this new feature to respond to your questions. Please submit your questions via e-mail to ASAT@autism-treatment.org, with Help Desk in the subject line.

Dear ASAT:

My child seems to put everything into his mouth-paper, stones, leaves, plastic, toys . . .

What can I do about this?

Pica refers to the apparent appetite for non-food items with no nutritional value. It presents a problem when the items are poisonous, pose the risk of infection, are otherwise harmful to health or might produce injury (as a result of swallowing something sharp.) Exploring objects by tasting and smelling is a universal human investigative technique which eventually diminishes based upon experience and learning. Babies explore many things with their mouths until "bitter experience" teaches them caution; many poisonous substances have a bitter taste, and parents are generally alert to prevent, stop or otherwise discourage inappropriate oral exploration. Most children gradually learn to discriminate edible objects visually, or based on the social cues and encouragements provided continuously by concerned caregivers.

Why do we explore things with our mouths? The organs of taste and smell are fundamental to learning about what is good to eat and where to find it. Babies are born with exquisite sensitivity to, for example, very small changes in sucrose concentration in a liquid solution. They demonstrate this

These measures should not be undertaken lightly or sporadically, because there is a risk from inconsistent implementation that the child could learn to be more secretive about pica.

sensitivity by changing the rate at which they suck a nipple to obtain a drink; concentrations increasing in sweetness by as little as 5 to 10 percent can slow the rate of suckling, as though the baby were savoring a more delicious treat. The tongue is almost ready-made for exploration, with more sweet receptors on the tip to guide the mouth toward high calorie and readily energizing sweets; bitter receptors are located at the back of the tongue to give warning not to swallow, and to expel dangerous or poisonous substances. The chemical receptors in the baby's nose serve to orient the face to accept nutrition efficiently, and they support rapid association of good smells with safe tastes. Mothers who eat distinctive foods throughout the last trimester of pregnancy will find

their babies prefer food with similar tastes and smells for a brief period after birth. Taste and smell preference can be maintained if the nursing mother continues to eat the distinctively flavored foods, because some of the chemical distinctiveness is carried in the milk she produces to feed her infant. Infants tend to prefer familiar sensations, with just moderate levels of novelty provoking some exploratory interest beyond the security of familiar sensations.

Furthermore, the lips and tongue are richly innervated with other sensory receptors for touch, pressure, and even pain, indicating that it is a very important information gathering site for the body. It is so rich with touch sensors, and these so effectively register the consequences of good tastes and good nutrition, that their stimulation is doubtless rapidly associated with goodness early in infant development, and is maintained in close association with good food and other social comforts for life in most people.

Is it any wonder that children explore things with their mouths?

Is it any wonder, then, that children explore things with their mouths? This is natural and nearly inevitable provided the sense organs are functioning properly. Unfortu-

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ASAT N.I.H. LIAISON REPORT

by Lawrence Lee, MD ASAT Board Member

In recent years, the National Institutes of Health have increased research into Autism Spectrum Disorders, with funding of nearly 40 million dollars. ASAT is honored to participate on the NIH Autism Research Coordinating Committee. This committee supports autism research at the National Institute of Child Health and Human Development (NICHD), the National Institute of Deafness and Other Communication Disorders (NIDCD), the National Institute of Neurological Disorders and Stroke (NINDS), and the National Institute of Mental Health (NIMH). Exciting developments are emerging on biomedical fronts, which may someday unravel the mystery of autism and how it affects our children. It is clear, however, that biomedical interventions based upon this research are unlikely to be available in the foreseeable future.

As a physician with a research background and as a parent of two sons, one with PDD, I felt well prepared to serve as ASAT NIH Liaison. What I was not prepared for was the way in which the National Institutes of Health are assaulted by pressure groups supporting pseudoscience, anti-science, and wishful thinking. Fortunately, the scientists in Bethesda usually have little difficulty discerning between pursuit of credible science, and unsubstantiated, vigorously promoted agendas. Unfortunately, however, there are a number of politicians, administrators, and lobbyists (not to mention families) who may not be so discerning. This, perhaps

more than anything, underscores the importance of ASAT's mission to provide honest, sound, evidence-based

The scientists in Bethesda usually have little difficulty discerning between pursuit of credible science, and unsubstantiated, vigorously promoted agendas.

perspective on issues important to the autism community, and to the search for effective intervention. ASAT's message has been warmly received in Washington.

In addition to the NIH Autism Research Coordinating Committee, ASAT is now regularly represented at the National Institute of Mental Health (NIMH) Research Roundtable, and at the National Advisory Mental Health Council (NAMHC). The NAMHC recently tackled the development of processes by which advances in behavioral science can be efficiently transferred to clinical settings. Dr. Jane Steinberg, Acting Director of the NIMH Division of Extramural Activities, invited me to contribute to the National Advisory Mental Health Council Behavioral Science Workgroup. Their report, "Translating Behavioral Science into Action" was recently released, and is available as NIH Publication 00-4699. The executive summary (and entire report) can be found on the web at www.nimh.nih.gov/council/bswsummary.cfm. ASAT is one of only three advocacy organizations (and the only one for autism) that were asked to contribute to the NAMHC report,

while all other participants are affiliated with either academic or government constituencies.

I have also been asked by Dr. Steven Hyman, Director of NIMH, to join the NIMH Data and Safety Monitoring Board. This board oversees NIMH's large multi-center experimental studies in childhood anxiety, bipolar disorder, ADHD and autism, as well as comparative drug studies in Alzheimer's and schizophrenia. We are tasked with maintaining the highest possible standards for the safety of the participants, while assuring that the most useful and meaningful data are developed. While I serve as an individual, I bring ASAT as my institutional affiliation. The work is, at times, exhausting, but this is exactly where I believe ASAT belongs. This is where science and individual people in need establish an interface, a beachhead, in the struggle to better understand and treat these disabilities.

We are making headway in our mission to position ASAT as a resource to government agencies seeking thoughtful and well reasoned perspective on issues important to autism research and intervention. ASAT is making a difference. As of today, our quests to discover what causes autism, and how biomedical interventions may have a dramatic impact on the disorder, remain unrealized. But we do know that effective intervention exists right now that can improve the lives of a sizeable majority of individuals with autism. It falls upon us to fulfill the promise of a rational and thoughtful evidence-based process of good science, on behalf of those whom we love. •

SCIENCE IN AUTISM TREATMENT **WINTER 2001** SCIENCE IN AUTISM TREATMENT **WINTER 2001**

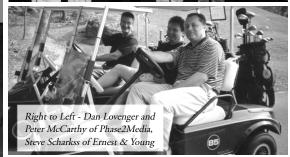
FIRST ANNUAL ASAT















Steve Quinn, Jim Stock, Jim Fallon

Phase2Media Foursome: Rich Nachmias, Len Frankel Andrew Eisner, Steven Bebe

Mark Murphy and Scott Ford of

Phase 2 Media, Dick Ford

The sun was shining and it was a perfect autumn day as golfers teed off at the start of the First Annual ASAT Golf Classic. The Centennial Golf Club in Carmel, New York provided a breathtaking backdrop to a beautifully designed and very challenging course.

"This is one of the most beautiful golf courses I've ever played," ASAT supporter Mark Murphy said. "The opportunity to play here while also raising awareness about ASAT's important work is truly a privilege, one I expect to make a yearly event."

The success of the event would not have been possible without the support of our many sponsors who gave so generously to help ASAT's cause and mission. ASAT would like to extend heartfelt thanks to Phase2Media, FreeLotto, NextCard Visa, Uproar.com, Net Creations, Wuliweb, B2B Works, Ernst and Young, Proskauer Rose LLP, Promotions.com, the Cortale Family,

(10)

Families are struggling so hard to find honest, sciencebased information about treatment. The importance of ASAT's mission cannot be overstated.

the Hughes Family, and Michele and David Lender for sponsoring the ASAT Golf Classic. In addition, we'd like to acknowledge the generous prize donations received from John Trimble and NFL Properties, Mike Kostel, and CarePackages.com.

Of course the ASAT Classic would not have been a success without the support of all of its contributors, too numerous to mention in limited space. The outpouring of generosity from contributors, golfers, sponsors and prize donors alike was overwhelming, and deeply appreciated.

ASAT would also like to extend sincere thanks to the Centennial Golf Club and its staff for their guidance in planning and conducting the event. Many thanks also to Nicole Weidenbaum and Michael Mannion for their volunteer services.

After a round of golf, the evening was capped by cocktails, dinner, award presentations and a silent auction.

"This evening has taught me so much about autism," attendee Andrew Eisner commented. "Prior to tonight I did not know how common this disorder is, nor did I have any idea how families are struggling so hard to find honest, science-based information about treatment. The importance of ASAT's mission cannot be overstated."

ASAT thanks everyone who made this premiere fundraising event a spectacular success. •

VOICES

Dear ASAT:

As an American posted abroad, I was unsure of where to turn when I found out my son might be on the autism spectrum. Hours after I contacted ASAT, highly valuable information and emotional support came pouring into my e-mail, and I no longer felt so isolated. Now I am pursuing several options of behavioral therapy thanks to ASAT.

N. FitzGerald, Berlin

Dear ASAT:

I got a copy of your fall 1999 newsletter, and I am very interested in your work. I am a child and adolescent psychiatrist at the University of Zurich, Switzerland, and I see autistic children and their families quite regularly. They and I are overwhelmed by all the information that comes in every day, mainly from the US, promising new treatments and great success for everybody. A critical review is deeply needed. . .

Sincerely, Ronnie Gundelfinger

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

THANK YOU TO OUR **SUPPORTERS!**

Vincent Casa, for donating his time and technical expertise to helping to create our newly updated computerized databases.

And a special thank you to Kim Donovan, SLP, and Jack Lickfeld, for their generous donation to ASAT on the occasion of their wedding on October 27, 2000. This donation was made in the names of wedding guests in lieu of favors. Kim is a speech-language pathologist currently working with children who have autism at Summitt Educational Resources in Tonawanda, New York. Congratualtions!