

SCIENCE IN AUTISM TREATMENT

Summer 2002

THE NEWSLETTER OF THE ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

Recovery: Debate Diminishes Opportunities

By Catherine Maurice,
ASAT Board Member

Recently, Catherine Maurice was asked to respond to a letter of invitation to contribute to a special issue of the online journal, *Leadership Perspectives in Developmental Disabilities*. The letter read, in part, as follows:

"For the fourth issue, we wish to engage experts and consumers from around the country in a debate concerning the merits of early intensive behavioral intervention (EIBI) for 3 to 7 year old children diagnosed with autism... We recognize that the concept of "recovery"

is hotly debated within the consumer and professional community; it is for this very reason we want to address the issue head-on, in order to start a dialogue about the merits of EIBI.

The working title for the fourth issue of *Leadership Perspectives* is, "Autism Recovery Intervention for Young Children: Does it Work?" Topic areas we are interested in publishing include:

- *Is the concept of recovery a useful term to use?*
- *Is there data to substantiate recovery?*
- *Is there evidence to imply that data suggesting recovery is an artifact of subject selection or other variables?*
- *Are recovery treatment procedures varied or similar in nature?*
- *What are the critical elements of any recovery treatment attempt?*
- *What are the barriers to providing recovery intervention?*
- *The workforce considerations associated with recovery intervention*



Noah, son of ASAT supporters Jim and Caroline Thibeault.

- *Are there ethical issues associated with recovery?*
- *What is the economic implication of wide scale recovery attempts?"*

Maurice's response is excerpted here:

It does not take an advanced degree in literary criticism to detect a certain level of skepticism in this letter. These questions seem rather biased against early intensive behavioral intervention¹ and the possibility of recovery from autism. Far from displaying any enthusiasm or even neutrality before either of these concepts, this letter seems to be inviting attack, from every possible angle.

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EDITORIAL*Education? Health Care?*

In some states, Medicaid and other health care programs will not fund science-based autism treatment because such services are allegedly really "education."

Let's explore that. If an adult has a stroke and loses the ability to talk, walk, use utensils, and care for himself, health insurance pays for intensive, competently-delivered rehabilitation that does not look much different from science-based interventions used for children with autism who have the same skill deficits. Are we suggesting the adult stroke victim should go back to college to learn these skills? Of course not. Yet some of our children with the medical diagnosis of autism are thrown only to the special education system for services.

Schools are not required to maximize a child's potential. Nor do they necessarily know how to do so, until they receive proper in-depth training. An emergency room physician who has a child recently diagnosed with autism sat at her child's Individualized Education Plan team meeting. She was seeking the documented 30 – 40 hours a week of science-based treatment for her son.

"That's optimal," the special ed professional said. "Therefore, we really only need to do 10 – 20 hours."

The physician, a professional trained to think competently under horrific stress, paused. Then she quietly said, "Let me tell you how I heard that. You come into my emergency room riddled with pain from a terrible accident. I should give you 10 milligrams of morphine to dull your pain while we help you, but I will only allow 5. — Which, by the way, will not stop the pain."

There's a lesson here. We just need to figure out what it is, and how to use

continued on next page

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.

it. One lesson may be that somewhere along the line we lost focus on the distinction between medically-necessary treatment for children with autism, and a “free and appropriate education” for children with autism.

Medically-necessary treatment is calculated to help patients recover from illnesses and disorders. If recovery is not possible, the medical community seeks to maximize a patient’s potential. The medical community evaluates its excellence, and ethics, based upon the patient’s outcome.

In contrast, and according to many Medicaid manuals, education consists of academic services in those traditional subjects as science, history, literature, foreign languages and mathematics. The education community evaluates its success in educating children with special needs based upon the child’s progress—not outcome. This progress is measured with varying degrees of accuracy, and is determined to be of educational benefit within a very broad range of interpretation.

The health care community, including all forms of health insurance, should ensure that our children receive autism treatment calculated to achieve



Jason, son of ASAT Board member, Lora Perry, and her husband Steve; with therapist Kate Hossler.

aggressive outcome objectives pursued for individuals with other medical diagnoses. Education should supplement autism treatment, not substitute for it.

When treatment provisions are in place to maximize the outcome of the patient’s diagnosis, then we can talk about excellence in education. We must also ensure coordination of services across educational and treatment domains, so that educational practices do not interfere with treatment.

Anything less does not serve our children.

- Lora Perry, MS, Editor

Snippets from www.Quackwatch.com FAQs:

Quackwatch is a nonprofit corporation whose purpose is to combat health-related frauds, myths, fads, and fallacies. Its primary focus is on quackery-related information that is difficult or impossible to get elsewhere. Quackwatch’s activities include investigating questionable claims, answering inquiries, distributing reliable publications, reporting illegal marketing, generating consumer protection lawsuits, improving the quality of health information on the Internet, and attacking misleading advertising on the Internet. Quackwatch is run by Stephen Barrett, MD. The following are quotes from the website, slightly abridged for length.

How do you respond to accusations that your writing is unbalanced?

Balance is important when legitimate controversy exists. But quackery and fraud don’t

involve legitimate controversy and are not balanced subjects. I don’t believe it is helpful to publish “balanced” articles about unbalanced subjects. . .

Do you believe there are any valid “alternative” treatments?

This question is unanswerable because it contains an invalid assumption. Alternative is a slogan, not a definable set of methods. Methods should be classified into three groups: (1) those that work, (2) those that don’t work, and (3) those we are not sure about. Most described as “alternative” fall into the second group. But the only meaningful way to evaluate methods is to examine them individually, which we do. We discuss this subject fully in our article “Be Wary of ‘Alternative’ Health Methods.”

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- Are there ethical issues associated with recovery?
- What is the economic implication of wide scale recovery attempts?

Just substitute the word “cancer” for “autism” and any “lay person” could detect a slightly subversive note: Are there ethical issues associated with recovery from cancer? What is the economic implication of wide scale attempts to recover people from cancer?

It seems to me that these questions amount to little more than a call for ammunition against the rising demand for science-based, effective treatment, which at this moment in time happens to be anchored in the field of applied behavior analysis. Yes, aiming for and achieving recovery from autism is expensive. So is chemotherapy. So is a lifetime of state-supported custodial care. Why would we not attempt to recover anyone from cancer, or autism? No, we cannot *guarantee* cure or recovery for anyone, but is that sufficient reason to lower the bar? Do we start deciding how many people should have access to science-based treatments for cancer? Do we start deciding how many children should have access to ABA?²

- Is the concept of recovery a useful term to use?
- Is there data to substantiate recovery?

The very form of the questions implies that the correct answer to both questions is “No, of course not.” Again, think of the implications if we asked: “Is the concept of recovery from cancer a useful term to use?” It is only when we already hold an assumption that autism is forever that we question whether the “concept of recovery is a useful term.”³

But let’s step back, and look at a more serious complication. What is problematic here is not only the implicit skepticism about recovery, but also the confusion, manifest in this letter and in much of the anti-behavioral backlash literature, between the goal of recovery, and the goal of bringing children effective treatment. We need to set *both* goals for our children, with the understanding that under our present system of knowledge, only some children will achieve the first goal, but all children with autism can and should be offered effective treatment. At the present time, it is behavioral intervention that has published the most documented success in enabling children to learn. Whether or not recovery happens, behavioral intervention offers more concrete evidence of effectiveness than any of the dozens of treatment options currently being touted as effective for autism.⁴

This letter uses a term, “*recovery treatment procedure*.” What is that? EIBI is not a “recovery treatment procedure” although it may have that effect on some children. All treatment should be designed to maximize a child’s learning potential, to bring him or her as far as we can. Is this letter implying that if you want to aim for recovery, you use EIBI (otherwise called “recovery treatment procedure”), and if you want to aim for something else, you use another kind of therapy? What other therapy would that be, and what data exist to support the effectiveness of that therapy?

No one I know has ever claimed that EIBI will produce recovery in all children. But we do know that intensive behavioral intervention can improve the prognosis for people with autism. Undermining the notion of recovery and then calling early intensive behavioral intervention a “recovery treatment procedure” is another way of dismissing behavioral intervention.

- Is there evidence to imply that data suggesting recovery is an artifact of subject selection or other variables?

When I showed this question to my husband, he laughed and parodied the classic prejudicial question: “When did you stop beating your wife?” Those of us who are veterans of the autism wars recognize this question. It’s an easy attack, constantly repeated. If a child recovers from autism, the old guard is sure to offer one of three possible explanations:

- 1) He was very high functioning, and “selected” for intensive treatment.
- 2) He was never autistic at all. (Sorry! We didn’t mean it!)
- 3) He was autistic, and still is autistic. Although he looks and acts recovered, he is actually a trained robot, conditioned to respond to certain stimuli - but, deep inside, still autistic.

If my own tone sounds impatient, I apologize. But, after a dozen years, I no longer know what it will take to convince the people in power that the data are there, have been there for a while, and their job is to pay attention to the data. Moreover, the data do not “suggest” that early intensive ABA is effective in remediating many symptoms of autism. The data demonstrate that gains achieved through such intervention are real, and enduring.⁵ There are data not only “suggesting” the possibility of recovery, but also validating it over time.⁶

Why is this topic of early intensive behavioral intervention, its value, and its ability to produce recovery in at least

some children still “hotly debated” at all? How many more decades will it take for the establishment to accept the evidence that already exists? It is astonishing to me that various special educators and psychologists keep calling for more data to substantiate the value of intensive behavioral intervention, and yet they themselves have produced no data to speak of that validate approaches such as play therapy, therapeutic nurseries, special education and psychotherapy. How much more *debate* do we have to engage in, as generations of autistic children founder?

It's easy to attack ABA by attacking the notion of recovery. But this controversy is not solely about recovery. This is not solely about defending the truth of any child's real and enduring recovery. This is a matter of knowing that a powerful teaching technology exists, but that parents are unable to access it for their child. It is a matter of knowing that parents can be blocked at every turn by a stonewalling establishment. It is knowing that only a handful of good behaviorally-based programs exist in this country, and that, if this resistance continues, we may not see any more any time soon.

- **What are the barriers to providing recovery intervention?**

Money, for one thing. A scarcity of trained providers in behavioral treatment, for another. *But professional skepticism and a refusal to accept hard evidence play into which programs get funded and which do not.* If a majority of those in power denigrate ABA, and deny the reality of recovery, only the wealthy or lucky will access this intervention for their children.

- **Are recovery treatment procedures varied or similar in nature?**
- **What are the critical elements of any recovery treatment attempt?**

These are, in fact, good questions, provided we substitute the phrase “Effective, data-based treatments” for the silly phrase “recovery treatment procedures.” The Association for Science in Autism Treatment (ASAT) is working on analyzing these and similar questions. We know there is still much work to be done in defining the critical components of effective behavioral treatment models, and in defining the critical skills and knowledge demanded of a qualified provider. It would be very helpful if the professional community could leave the *debate* stage behind, and help us in our attempts to bring accurate information to families, and increased access to effective treatment.

I work with people whose children have not recovered. They and I hope that some day science will produce an easier, faster, and more effective treatment than that promised through ABA. We hope that current research on neurobiology, immunology and genetics will lead us there. But meanwhile, we know that ABA can offer children and adults with autism increased opportunity for learning, and in some cases, for recovery.

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1 When I refer to behavioral intervention, applied behavior analysis (ABA), or early intensive behavioral intervention (EIBI), I mean intervention that employs the principles and methods of behavior analysis, not generic early intervention programs that purport to be “behavioral” but actually employ only a few superficial behavioral techniques.

2 Jacobson, J.W., Mulick, J.A., & Green, G. (1998). Cost-benefit estimates for early intensive behavioral intervention for young children with autism: General model and single state case. *Behavioral Interventions*, 13, 201-226. [Offers a well-reasoned analysis of this topic]

3 The question is illogical as well because the word *concept* is being used to mean the word *term*.

4 Clinical Practice Guidelines: Report of the Recommendations. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children, 1999 Publication No. 4215. New York State Department of Health, PO Box 2000, Albany, New York 12220.

5 For an overview of research on this subject, see: Green, G. (1996). Early Behavioral Intervention for Autism. What Does Research Tell Us? In C. Maurice, G.Green, and S.C. Luce, (Eds.), *Behavioral Intervention for Young Children with Autism: A Manual for Parents and Professionals*, Austin, TX. Pro-Ed.

Clinical Practice Guidelines: Report of the Recommendations. Autism/Pervasive Developmental Disorders, Assessment and Intervention for Young Children, 1999 Publication No. 4215. New York State Department of Health, PO Box 2000, Albany, New York 12220.

6 Lovaas, O.I. (1987). Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*, 55, 3-9.

McEachin, J.J., Smith, T., & Lovaas, O.I. (1993). Long-term outcome for children with autism who received early intensive behavioral treatment. *American Journal on Mental Retardation*, 4, 359-372.

Perry, R. Cohen, I., & DeCarlo, R (1995). Case Study: Deterioration, autism, and recovery in two siblings. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34, 232-237.

BEHAVIOR ANALYST CERTIFICATION BOARD UPDATE

Gerald L. Shook, Ph.D., BCBA
BACB Executive Director

The Behavior Analyst Certification Board (BACB) received 385 applications for examination for the May 2002 exam administrations. Exams were being offered in 17 cities in the United States, as well as in Toronto, Canada and Cambridge, England. This represents a significant increase in the number of applications received for a given administration.

Fall administrations are scheduled for Saturday, November 23, 2002. Individuals who are interested in having the examinations administered in their area in November, or who are interested in BACB presentations at their conferences, should contact the BACB Executive Director.

The College Teaching Option (Option 3) for qualifying for the Board Certified Behavior Analyst examination expired on June 30, 2002. College Teaching Option applications for examination and documentation materials are no longer accepted.

The Behavior Analyst Certification Board and the State of Florida, through Professional Testing, Inc., have conducted a formal job analysis survey of 1,519 behavior analysts in 26 countries. The purpose of this analysis is to update the BACB Behavior Analysis Task List content that is used in constructing the examinations. The results, with an analysis of implications for the field, were presented at the Association for Behavior Analysis convention in Toronto. Also in Toronto, Behavior Analyst Certification Board staff presented a BACB update session, and were available to answer questions in the

BACB information booth.

The BACB Continuing Education Committee is accepting applications for the approval of Individual and Organizational Providers who wish to offer "approved" continuing education events for certificants. Details of this process and applications are posted on www.BACB.com.

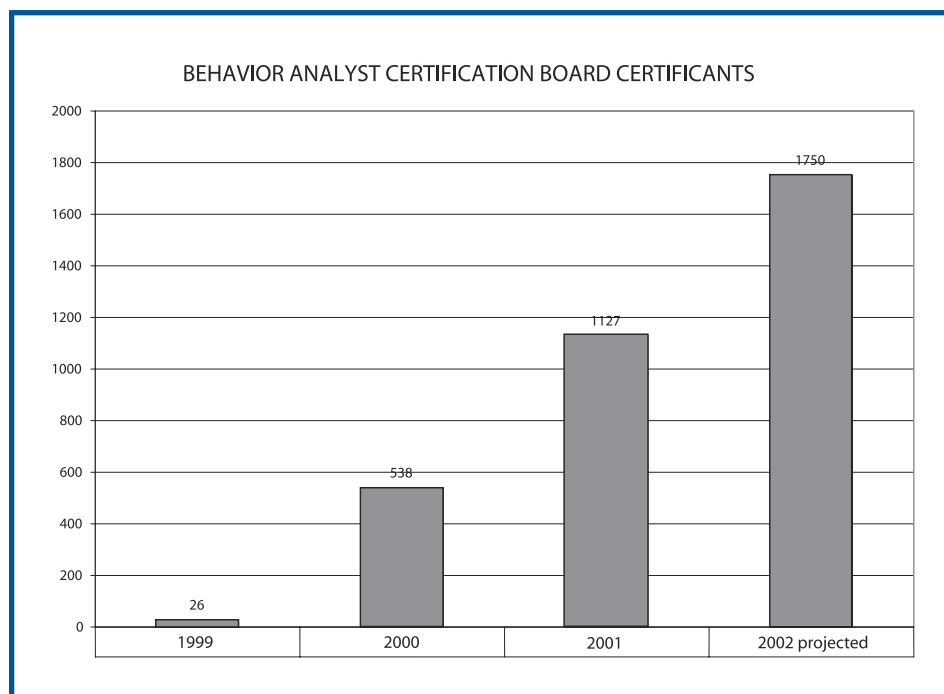
International developments:

- a consortium of Japanese behavior analysts has translated the Behavior Analyst Certification Board's Behavior Analysis Task List into Japanese
- the United Kingdom ABA Lecturers Co-operative has developed coursework to prepare individuals for the Board Certified Associate Behavior Analyst examination
- faculty at University of Auckland are developing a Master's program

to prepare individuals for the Board Certified Behavior Analyst examination, with plans to have the examinations administered in New Zealand.

Please refer to www.BACB.com for complete information on the Behavior Analyst Certification Board, including a registry of certificants, an expanded listing of universities with approved graduate course sequences, new state certificant transfer opportunities, the BACB Guidelines for Responsible Conduct for Behavior Analysts, certification examination eligibility standards, and applications for examination.

The Behavior Analyst Certification Board congratulates Gina Green, who has been named as the newest member of the BACB Board of Directors. Dr. Green also chairs the BACB Continuing Education Committee, working with Siri Ming and Michael Hemingway.



ASAT

HELP DESK

Bobby Newman, PhD, BCBA

Dear ASAT:

Question: My son's progress in programs is often nothing short of phenomenal. He masters skills quickly, but then seems to lose the skills he has. We feel like we're on a treadmill. Help!

Answer: Unfortunately, this is a common dilemma. The good news is that this problem can be addressed. The bad news is that it means really looking at how you're teaching, and possibly making some changes. Let's first agree upon some vocabulary in everyday language:

1. ACQUISITION: the learning of the new skills and concepts.
2. STIMULUS GENERALIZATION: learning to perform a skill under different conditions.
3. MAINTENANCE: the continued performance of the skill after the formal, intensive teaching period has ended.

From your description, your son is doing fine during the acquisition phase. But is he really acquiring the skills? A common problem is that the acquisition phase is conducted far too narrowly. Given a receptive program, for example, do you and your therapists *always* say "touch," as opposed to "give me" or "point to" or "show me" or "which is," or some other phrasing? Do you *always* use the same stimuli (for example, always using colored construction paper for color ID)? If we have always taught using

colored paper, it is very difficult for the child when we ask him, for example, the color of a toy car. If he has always heard "what is your name?," it is then not surprising if he cannot answer "what is your *first* name?" Teaching needs to be precisely structured, but not so limited that generalization becomes impossible. Some people call this "loose teaching." As simple as it sounds, it can be very difficult—most people need to be taught how to loosely teach. But it's worth the effort. You get what you teach.

How then, can we encourage generalization? Basically, we are looking at the "Dr. Seuss" school of teaching: do it in a box and with a fox, in a house and with a mouse, etc. Vary where you do your teaching. Vary phrasings to make sure that you hit the common ways that people speak (e.g., "hi," "how are ya," "hello," "how ya doin?"). Wear glasses, and don't wear glasses. Practice skills in the morning and in the evening, in the house and in the car. Some schools and programs prefer to do generalization training from the very beginning, by varying instructions and stimuli from the beginning. Others use precise and consistent phrasing and stimuli first, and then conditions are varied once mastery is achieved with the original phrasing and stimuli. You will find advocates of both approaches. Using the more limited stimuli strategy, you will probably see faster acquisition, but then you need to aggressively program for generalization. If you vary stimuli from the outset, you will probably see somewhat slower acquisition, but you will have the payoff of easier generalization. My own preference is to generalize from the beginning.

For Maintenance, you need to follow

a similar plan. Remember that with children who have autism, we must consciously plan to help the child acquire, generalize and maintain skills. If you want to continue seeing a skill, it must be practiced. Too many programs focus only on the most current step (e.g., "touch your belly") and fail to continue practice on the previously learned steps. Where I come from, each teaching session includes a block of the new step ("isolated"), and a block of all the previously mastered steps ("randomized"). Even when the full program is learned, we return to it periodically for a practice session, or we incorporate the skill into new activities (e.g., working on mastered body parts in a "Simon Says" game).

Also remember that you need to work on concepts, and not just responses. When doing body part ID, for example, don't always ask the child to touch *his* nose. Ask him to touch his nose, your nose, the nose of a doll, the nose of a stuffed animal, etc. We want your son to know what noses are, and not just think that the bump on his face is named nose.

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Order conference tapes
Review past issues of the newsletter
Solid, science-based information
Suggested reading list

ASAT

ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

PLEASE GIVE

2001 was another outstanding year for ASAT. More than 35,000 copies of *Science in Autism Treatment* (SIAT) 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 SIAT via phone, fax and e-mail daily, as well as compelling testimonials from individuals directly benefiting from the newsletter's content.

Also during 2001, we went online with our website at www.asatonline.org. The website offers direct and useful in-

formation about autism, a suggested reading list, answers to frequently asked questions, previous issues of *Science in Autism Treatment*, links to other credible autism sites, and much more.

The conference **ABA: Maximizing the Potential of Children, Parents and Teachers** in Portland, Maine was attended by more than 200 people, despite disruptions caused by the terror attacks on September 11 only 10 days before. Presenters included Catherine Maurice, ASAT Board member and author, Randy Horowitz from the Genesis School, Joanne Gerenser from the Eden II Programs, and Peter Gerhardt from Rutgers University.

ASAT continued to support the efforts of the **Behavior Analyst 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 intern-

ship 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.

But much remains to be done. Over the next year, ASAT will continue to produce and distribute *Science in Autism Treatment*. Our website will be updated and expanded to make it even easier to access science-based information about autism and treatment.

With your 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 by mailing your tax deductible contribution to ASAT, PO Box 7468, Portland, ME 04112.

THANK YOU!

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