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Facilitate This: Part I of a Two-Part Interview with Dr. James Todd
By David Celiberti

Thank you so much for taking the time to participate in this two-part interview. I am grateful for this opportunity to share some of your experiences and perspectives with SIAT readers in Part 1 of this interview.

Our readers should know that you have previously served on ASAT’s Board of Directors. Please tell us a bit about your background and how this prepared you in assuming the role of a staunch advocate for science.

I was always interested in science, so much so that one of my grade school librarians actually tried to ration my science consumption by forcing me to check out at least one fiction book per week in addition to the math and nature books I was addicted to. Once I hit high school, that reading shifted to Isaac Asimov, George Gamow, and the other classic scientist-popularizers. Asimov, in particular, showed a healthy disdain for charlatans and cranks, and I enjoyed his skillful dismembering of their often bizarre and scientifically vacuous claims. I also had a collection of magic books, including Joseph Dunninger’s Complete Encyclopedia of Magic, Milbourn Christopher’s Panorama of Magic, and a biography of Harry Houdini. I hoped to be able to do magic, but never became very good at it. However, because of those three books, it became clear to me that people interested in magic were often interested in exposing frauds, and that frauds often employed the same types of deception, misdirection, and secret cues from confederates that conjurers used.

Dunninger was a “mentalist,” a “mind reader,” so in reading about mentalism I also came to know about the trick of looking for “anticipatory tension” in those being tricked. It is not a big leap from that to understanding that your subjects can, and will, unconsciously tell you almost anything you need to know if, as a result, you tell them “―read.‖ It is not a big leap from that to understanding that your subjects can, and will, unconsciously tell you almost anything you need to know if, as a result, you tell them “―read.‖

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Message from ASAT President, David Celiberti, Ph.D., BCBA-D

Happy Spring and Autism Awareness Month! With the increasing number of children being diagnosed, the widespread availability of Internet-based information (of course, not all of which is accurate), and the rise in social networking sites such as Facebook and Twitter, more and more people are talking about autism spectrum disorders, as well as their identification, assessment, and treatment. I wish the autism community had its own internal calendar where particular monthly topics could garner attention such as early intervention, sibling support, preparation for adulthood and so on; however, values such as accountability, respect for science, and data-based decision making must always remain in the forefront.

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Facilitate This: Interview with Dr. James Todd continued...

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what they want to hear. I also knew from my magic reading that if you want to know how the trick works, it is better to watch what the magician does in relation to the trick rather than the effect itself. As Yogi Berra is said to have said, “You can observe a lot just by watching.” What all this amounted to was an education in the basics of experimental methodology, and ultimately led to appreciating behavior analysis as an authentic science of behavior and an incredible tool in tackling the vast array of pseudoscience facing families of children with autism.

Please share with our readers how you became involved in challenging proponents of facilitated communication.

When I first heard about facilitated communication (FC) in 1990 or 1991, it was instantly clear that I was seeing a version of a trick already well-established by mentalists over 300 years ago, and described in magic books as early as 1805—except that the facilitators unconsciously did the trick on themselves! (I will speak more about that at the ABAI convention in San Antonio.) It was also clear what had to be done methodologically in order to show that the facilitator was the source of the output. A lot of the FC that I saw was so incompetently done, with the child’s hand being clearly pushed around by facilitators. I was astounded that anyone believed it, or would tolerate such a thing being done to helpless children and their loved ones; much less endorse, encourage, and teach it. Believe they did, however. And, like drug dealers, only with Ph.D.s and academic appointments, they pushed it on desperate parents. Back then, in the early 1990s, Peter Holmes took the lead on FC with the Behavior Analysis Association of Michigan (BAAM). He showed how to engage the FC advocates directly, inviting them to debate at the BAAM conference. I joined in this, doing things like debating proponents publicly for the Eastern Michigan Psychology Club, and then incorporating information about FC into most of my classes.

Can you tell us a bit more about the debate? How did the proponents counter concerns about FC and how was this received by the audience?

I debated Sandra McClennen, who was then a Professor in the Department of Special Education here at Eastern Michigan University and a licensed psychologist. That was December 1, 1994. She is now Emeritus and still a licensed psychologist. She was an early believer in FC, and has promoted it heavily since then. She continues to spread its word, and in fact, is scheduled to do a workshop on FC in Plymouth, Michigan this spring. She was involved with the Syracuse University Facilitated Communication Institute (FCI), and is credited for helping the FCI formulate the “Facilitated Communication Training Standards.”

We did one of those show debates, very civilized and polite, with both of us taking turns as academics do. It was not a debate McLennan could win. It occurred a little more than a year after the first broadcast of the PBS/Frontline exposé of FC, “Prisoners of Silence” in October, 1993. Nearly everyone in the standing-room-only audience of about 50 had seen it. There were by then a fair number of methodologically reasonable studies of FC available showing that FC did not work. I also knew all the FC arguments because I had a large collection of background materials supplied by Gina Green, Pat Meinhold, and Bernie Rimland. McLennan, for her part, led with neurological research by Eric Corchesne that supposedly implicated the cerebellum in autism; buttressing, she claimed, the FC advocates’ theory that autism is really a disorder of motor planning and control. She made a lot of a small study by Calculator and Singer (1992), published as a letter-to-the-editor, which FC advocates continue to claim shows the successful use of FC with non-verbal people on the Peabody Picture Vocabulary Test (PPVT). In that study, the facilitators wore headphones during the presentation of PPVT items.

Unfortunately for McClennan, the brain information to which she referred was so non-specific that it did not help her case; nor did the fact that it is very easy to find people with severe autism who have excellent fine-motor control. The Calculator PPVT study was fatally flawed because (1) its baseline consisted of giving the PPVT to subjects without using FC rather than doing FC with facilitators hearing the questions to show the contrast between facilitator awareness and lack of awareness of the questions (this is what I have started calling the “Erroneous Baseline Design”) and (2) the researchers admitted that the headphones did not fully mask the speech of the questioners. I also was able to quote silly statements from FC advocates, creating skepticism in their collective credibility. They were already arguing, for instance, that double-blind tests for FC were

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Facilitate This: Interview with Dr. James Todd continued...

methodologically invalid because people with autism possess psychic abilities and can directly read the thoughts of the facilitators (Haskew & Donnellan, 1993, pp. 13-14, 22-23). Here is an example of what I am talking about from a 1993 book on FC by Paul Haskew and Anne Donnellan:

A special education teacher told us she found that having students apparently conspire telepathically was the most troubling aspect of their mind reading abilities. However, once she recognized what was happening she dealt with it as any competent teacher handles an unruly classroom; her students quieted down, and stopped abusing their telepathic skills. (Haskew & Donnellan, 1993, pp. 22-23.)

The cool thing about quoting stuff like that is that your opponent has to either discredit herself by agreeing with absolute nonsense, or distance herself from her own sources.

The real problem for McClennen, however, was in launching a technically naive and poorly conceived response to a clip from the Frontline exposé. Frontline showed Rosemary Crossley, credited with establishing FC in Australia, facilitating with a man who was in a coma. He was supposed to be selecting words on a card with a head pointer. By drawing a line on the screen across the top edge of the card, Frontline revealed that Crossley was moving the card behind the man’s nearly stationary head pointer. McClennen argued that the two-dimensional TV picture could not show that the card was actually tilting back beneath the pressure of the head pointer. She promised that if there was a line at the bottom of the card, and one around Crossley’s thumb, we would see that the card was being pushed back by the man, creating the illusion that Crossley was moving the card. I anticipated this argument, and came prepared with a set of dry-erase markers. I actually drew the exact lines McClennen suggested right on the television screen to prove that the card was moved by Crossley exactly as Frontline said.

Despite ample data disputing these claims, FC does not go away. How are proponents of FC able to appeal to parents so successfully on an emotional level?

Data-shmata. There is more crying in baseball than data in most autism treatments. FC is just the tail end of a data-free treatment spectrum. It’s all about motivation and impulsivity.

Miguel Cervantes, who knew all about establishing operations, hit the nail on the head when he wrote in 1615, “La mejor salsa del mundo es la hambre; y como ésta no falta a los pobres, siempre comen con gusto;” “Hunger is the best sauce in the world; and since the poor are never without it, they always eat with gusto” (Don Quijote, 1615, Parте 2, Capítulo V). Facilitated communication advocates promise desperate parents that FC, which is easy to do and costs virtually nothing, can release their children from the prison of autism.

The advocates of FC layer on a patina of sciencey-sounding flummery to the effect that autism is actually a motor planning defect that blocks expression rather than involving cognitive deficits that prevent normal expression in the first place. What is really being sold, however, is the “miracle.” That is why you can go to FC events and workshops, including those sponsored by the Syracuse University Facilitated Communication Institute, and see weeping parents report that their child; who has never before spoken, read, or written anything meaningful; has just typed “Mommy I love you” with the help of a hero-facilitator. Who wouldn’t want something like that for their child or themselves?

As for impulsivity, we are confronted with a real-life Rachlin and Green (1972) experiment when we see FC advocacy in operation. Behavior analysis offers a much better, genuine reward backed up by bona fide science. The trouble is, that this big reward can be delayed and involve a high response cost. FC is proffered as virtually certain reward that comes sometimes instantly, but at least as soon as the kid seems to type anything that can be interpreted as something. We saw this in the PBS/Frontline documentary “Prisoners of Silence.” A desperate mother, another victim of the “I love you mommy scam” at the hands of a Syracuse-trained facilitator, facilitated “IMSNOS” with her daughter. That typing was then interpreted as the child saying, “I miss father;” with “father” being expressed as “NOS” because the father would sometimes touch his nose in an entertaining way.

You raise an excellent point about impulsivity. Autism has a significant impact on a child’s social relatedness, communication skills, and ability to learn across all domains. It would be naive to think that a simple intervention such as a swim with a dolphin or a session

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with a facilitator could eradicate such profound deficits.

The media continues to keep FC on the radar for new generations of parents. Why do you believe FC keeps garnering such widespread media attention?

The media attention is no surprise, of course. FC is a medical miracle. Aside from a political sex scandal or whatever Lindsay Lohan might be doing, nothing attracts a reporter’s attention more effectively than a medical miracle. We saw this late last November with the Rom Houben debacle. Houben, a man in Belgium, has been in a deep coma (or worse) for over 20 years, saying and doing nothing purposeful as far as anyone can determine. Suddenly, with the involvement of the up-and-coming brain scientist, Steven Laureys, Houben was not only designated “fully conscious,” he was said to be capable of expressing himself verbally through “new technology.” The result was a worldwide, multilingual media circus with Dr. Laureys as ringleader. (I use the term “circus” loosely here as I have noted circuses to be models of understatement and nuance relative to the coverage of Mr. Houben’s apparent awakening.) The “new technology” was FC.

The problem was that some of the videos accompanying the story showed Mr. Houben slumped in his wheelchair, his eyes closed and facing away from the keyboard, while an aide used his finger to type. Seeing these things on MSNBC, Hank Schlinger and I immediately contacted various media-connected people. Hank was even booked for a TV interview which, as often happens in TV, didn’t happen. I emailed University of Pennsylvania bioethicist Arthur Caplan, who, to his immense credit, looked into the matter and within a day injected the FC angle into the mainstream news stories. That’s when the questions began. The public realized it had been bamboozled, and Dr. Laureys’ ability to backpedal was severely tested. In fact, the facilitator control in the Houben’s videos was so clumsy and glaringly obvious that even the usual FC advocates did not rise up to defend it. We really have to wonder why no one in the media, from Al-Jazeera to MSNBC, initially questioned the validity of the obviously bogus typing, or why no one seriously challenged Laureys’ use of FC as evidence of Mr. Houben’s allegedly intact consciousness.

Of course, the media often do not ask the right questions or challenge the claims. This is nothing new—although it might be worse now. And there seems to be something about autism that amplifies this effect. Why else would we see stories about kids being pressurized, drugged, weighted down, selectively malnourished, and otherwise experimented upon with so few reporters freaking out and asking, “You actually do that to little kids?” For a historical perspective, I’d suggest reading Pope Brock’s book *Charlatan*, which is about “Doc” Brinkley’s infamous and sometimes fatal “goat gland” operations to restore male virility. Media pressure and official investigations drove Brinkley underground and eventually out of business. We see little of this in autism, where almost every claim seems to get the instant credibility of a fawning feature report and, unless it involves restraint or seclusion, zero official or public concern about safety or proven effectiveness. For instance, I have found only a few isolated mainstream media objections to extravagant claims in the 2005 CNN-produced, Oscar-nominated FC-promoting movie, “Autism is a World.”

http://tinyurl.com/asatTodd1
http://tinyurl.com/asatTodd2
http://tinyurl.com/asatTodd3

But, other than what I found in the *Jerusalem Post, Pasadena Weekly*, and *Washington Post* (which then, as we see in the link, undercut its own writer by issuing a “correction” to her doubts about the validity of FC), the general reporting on that movie, like almost all FC coverage, was credulous and gushing. And I think “credulous” is the right word. CNN’s Chief Medical Correspondent, Sanjay Gupta bought it—accepting, with no empirical proof at all, that the barely verbal Sue Rubin wrote “Autism is a World” using FC. We really must demand better from a brain surgeon and member of the Emory University Medical School faculty.

Bringing things closer to today, NBC technology reporter Scott Budman didn’t seem to care last year when he observed the staff at the Hope Technology School in Palo Alto, California guiding kids’ typing with sticks, just as is recommended in the FC books, very literally turning the children into rod-puppets. Didn’t anyone involved in that story wonder what the adults were doing at the other end of those sticks? In August 2009, the *Boston Globe* attached a video of FC to an online story about a $29 million gift from the FC-loving Nancy Lurie Marks Foundation to Margaret Bauman’s

“Of course, the media often do not ask the right questions or challenge the claims.”

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Ladders Program at Massachusetts General Hospital. The video showed typing attributed to David Surett, for whom Bauman serves as advocate, controlled by his mother moving his forearm around with two hands. Bauman is a well-known neuroscientist, but has an alternate identity as a FC advocate who appeared in “Autism is a World,” and co-authored a 1996 article of astonishing badness in Mental Retardation “validating” FC (Weiss, Wagner, & Bauman, 1996). (The correct answers were given, Clever Hans style, only when someone who knew the answers attended the test sessions. It is the kind of journal article that a functional peer-review process would have never let see ink, and from which a genuine scientist would withdraw support.)

But, I’m getting far afield. The point is that we should have been able to expect a Boston Globe reporter to ask why Mr. Surett needed his mother to type for him, or, better, why someone associated with Ladders apparently continues to advocate a dangerous, long-discredited, and scientifically repudiated intervention. See:

http://tinyurl.com/asatTodd4

Why is it like this? How have we arrived at a situation where almost no one is pulling back the curtain on these things, where we are more likely to see a serious interview with a real scientist on Comedy Central’s “The Daily Show” than anywhere else on TV? I think the answer lies in John Burnham’s excellent and underappreciated book, How Superstition Won and Science Lost. Burnham, a historian at Ohio State, acknowledges that all was not perfect in the past, but argues that things really have changed for the worst. Magical thinking has become pervasive in the reporters’ analyses along with a significantly decreased willingness to directly challenge claims even from a “common sense” perspective. His technical argument is that science reporting has shifted from discussions of process to discussions of outcome. Everything becomes, in essence, a gee-whiz miracle, and one whiz is as good as another. Couple that with the near extinction in the mainstream media of scientist-popularizers like Isaac Asimov and Carl Sagan; who were accessible models of good scientific thinking; and the result has been a tsunami of credulous feature reporting displacing bona fide science journalism.

What lessons should advocates of scientifically-validated treatments learn from the resilience of so many pseudoscientific treatments?

That pseudo-science is like the yellow cat in the old song. You can’t get rid of it by any ordinary means, and it just keeps coming back. If the usual methods worked, we wouldn’t be here talking. Bogus and ineffective treatments proliferate in any environment that does not have an obviously effective treatment. Until then, you’ll be playing whack-a-mole with them. And, we have to accept that we have not yet figured out how to reliably teach those much-vaunted “critical thinking skills” that supposedly immunize people against magical thinking and pseudoscientific beliefs. Even when we occasionally succeed, the skills are often domain-specific—critical thinking in chemistry; critical thinking in geology. We have not figured out how to get good scientific thinking to reliably generalize across any individual’s behavior. That means that pseudoscience will pop up in the most unexpected places—like in your otherwise clever colleagues’ verbal behavior. History is full of famous examples. William James, who wrote some of the major founding documents of psychology in America, was a believer in psychic phenomena. Lightner Witmer, considered by many to be the founder of modern clinical psychology, was taken in by a trained circus chimp named Peter, thinking it perhaps a kind of missing link, and doing all manner of tests of its supposed abilities. It’s no different now. Just in the last few months we have seen Steven Laureys, who is by most accounts a top-notch neuroscientist, falling for some of the most incompetently done FC I have ever seen. And he’s not alone. Syracuse University Chancellor Nancy Cantor is not only a Ph.D. in Psychology from Stanford University, she is perhaps the nation’s highest-ranking academic advocate of FC. In a 2007 speech entitled, “Imagining America; Imagining Universities: Who and What?” Cantor left no doubt about her impatience with science for generating controversy about something she says has proven by anecdote and testimonial:

And while the controversy about facilitated communication in the research literature in psychology and education never seems to tire, the compelling testimony to its power is written and rewritten in the stories of autistic individuals, turned public scholars, college students (including Jamie at Syracuse), actors and filmmakers and writers, whose lives it has turned around – and freed.

http://tinyurl.com/asatTodd5

When you read Cantor’s whole

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speech, try not to be too taken
aback by her apparent comparison
of FC with freeing the slaves and
achievements in women’s rights.

You nailed it, as did Albert Einstein,
when he said, "Insanity is doing the
same thing over and over again and
expecting different results." You
have been at this for many years.
How has your approach to
challenging pseudoscience evolved
over time?

Well, you do have to hone your
whack-a-mole skills. And you can be
driven crazy by having to do the
same thing over and over. You are
right, though. Different things come
up at different times requiring
different kinds of responses. You
have to know when to attack it head
on, when to be subtle, when a
strategic retreat is prudent, and
when to pick another battle. We
have written letters, made personal
contacts, worked through the
courts, consulted with the media,
posted on blogs, pulled rank, been
charming, been indignant, and even
issued genuine offers to do
independent validation tests on
claims of successful FC. If I ever get
a free moment, I am going to finish
the three or four FC manuscripts
scattered across my desk.

No matter what, preparation is key.
I have tried to know all there is to
know about FC. If called upon to do
so, I’d like to be able to make a
better argument for FC than the FC
advocates can. This means buying
and reading all the FC books I can
get – some of which are truly weird;
invoking angels, ESP, and math with
totals far beyond 100%. It means
attending FC training workshops,
and speaking to FC advocates. It
means finding and reading all the
academic literature on FC, including
theses and dissertations, including
the growing non-English literature,
and essentially memorizing the
published empirical studies. It is
especially important to know those
few studies that the FC advocates
claim to demonstrate successful
FC. They do not. They are true
methodological nightmares. These
disasters come up in court and are
cited in textbooks, and must be
rebutted. Of course, it’s the Internet
age. That means having Google
alerts to “facilitated communica-
tion” and related terms, reading the
blogs of FC advocates, and studying
the sites of treatment providers who
use FC. We also have to keep up
with those academics who endorse
FC and other forms of autism
pseudoscience.

If anything has changed, I think my
personal approach has become
more direct. I don’t hesitate to say
certain things that are true: That FC
has failed every test of science; that
it has never once worked under
properly controlled conditions; and
that facilitator control has been
repeatedly shown to be its primary
mechanism of operation. These
things are the baseline. I believe it
is a moral obligation to say that FC
is a fundamental human rights
violation. Its use not only prevents
the person with autism from
learning real, functional
independent living skills, but it
replaces the real person with a
fantasy identity of someone else’s
making. All that said, we must be
exceedingly careful in dealing with
the parents and caretakers who
have been taken in by these cruel
frauds. Smart people can be fooled,
and once it happens they are in a
trap. They have multiple
investments that simply cannot be
divested without significant
psychological cost. No one wants to
admit being taken in by a fraud. No
one wants to discover he or she
could have done something better
for a child. If it’s FC, they will not
want to admit they have been
talking to themselves and not the
child for months or years. They will
do pretty much all the things that
the social psychologists and
Freudians say they will in these
conflicted situations: Discount,
Deny, Rationalize, Project, Displace,
and Avoid. None of it will help them
come to the correct conclusion.

Tell us about how you address this
matter on the BAAM website.

The most visible thing we have
done has been adding a list of
signatories to the BAAM resolution
repudiating facilitated
communication. The resolution
itself was created in 1998 in
response to the very heavy
promotion of FC in Michigan by a
member of Eastern Michigan
University’s Special Education
Department. Something had to be
said, especially to help back up
those Michigan behavior analysts
who were finding FC pushed on
them in the workplace. We
essentially reworked and combined
ideas from some of the existing
resolutions, and made what we
believe is the strongest of all of
them. Please see:

http://tinyurl.com/asatTodd6

The signatory list was added in

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2005 in response to the airing of the FC movie, “Autism is a World,” on CNN. Again, something had to be done. CNN, “The Most Trusted Name in News,” was actually sponsoring the promotion of dangerous autism pseudoscience, and even broadcast the show without commercials to schools during the day as an educational opportunity for kids. We solicited signatures from BAAM’s mailing list, and collected about two hundred in the first few weeks. The President of the Oakland County Michigan chapter of the Autism Society of America wrote objecting to the resolution. Interestingly, the group was sponsoring FC training at about the same time and took exception to the BAAM Resolution. That prompted James Randi to issue his $1,000,000 challenge to the Oakland County chapter to demonstrate valid FC. We put a copy of Randi’s letter to the Oakland County group on the website, and even scheduled Mr. Randi to speak on the issue of medical pseudoscience at our 20th anniversary convention. Boy, did we get hate mail for that! See:

http://tinyurl.com/asatTodd8

The BAAM resolution now has about 450 signatories from people all over world. It has sensitized many people to the continued menace of FC. It has even been introduced in court cases as evidence for the repudiation of FC by the scientific community.

I am also quite proud of our coverage of the FC-sex abuse case in Bloomfield Hills, Michigan. BAAM’s was the most detailed of all the coverage, describing how a man and his wife had been accused through FC of raping their daughter for several years. We had extensive details about how nothing in the original accusations was credible, with critical details being apparently made up by the facilitator to fill out the story. The dog named in the record was dead and was given the wrong name. There was an extra grandmother, and two extra grandmother’s names. This observant Jewish family was suposedly espousing Christian theology. The girl, who could supposedly do middle-school work and write poetry with FC was unable to correctly or reliably spell her brother’s three-letter name, but could accurately spell her facilitator’s nine-letter name. There were rooms that didn’t exist, a gun that didn’t exist, and photos that didn’t exist. Facilitated statements that the parents had visited the daughter in violation of a court order were believed over the denials of the Orthodox Rabbi entrusted by the court with the care of the girl. We were among the only ones with coverage which accurately described what the judge meant when he said of FC that he “didn’t find anything scientific about it.” What that means legally is that FC is not a scientifically-derived method that can be challenged as to general reliability and validity. In other words, the judge agreed with the FC advocates’ view that FC should be treated by the courts as “interpretation,” like translating Spanish to English (Phipps & Ellis, 1995). Science was out; superstition was in. The upshot of it all was that despite “testimony” so self-evidently incorrect and inconsistent; produced using a technique supported by no bona-fide scientific or professional organization, that had been thoroughly repudiated by the scientific evidence, and even questioned by the prosecution’s own expert as well as both of those on the defense; the prosecution went on and an innocent man spent 80 days in jail. Worse than that was what FC led to for the girl’s brother: He was secretly plucked from school and interrogated for almost two hours without benefit of counsel or child services protection, and was led to believe that he had been videotaped participating in the rape of his own sister. We didn’t have the exposure and impact of the excellent Detroit Free Press coverage, but ours remains available for the record. See:

http://tinyurl.com/asatTodd9
http://tinyurl.com/asatTodd10
http://tinyurl.com/asatTodd11

I should also mention our compendium of other resolutions against FC on the BAAM website. As far as I know, it is the only place where one can find so many science-based statements on FC in one place. It too has been used in court cases.

Thank you for an incredible interview. Your perspectives on pseudoscience in general, and facilitated communication specifically, were interesting and enlightening. Your use of the BAAM website to address these matters

“"I believe it is a moral obligation to say that FC is a fundamental human rights violation. It's use not only prevents the person with autism from learning real, functional independent living skills, but it replaces the real person with a fantasy identity of someone else’s making.”

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should be a wakeup call for other organizations to take a stand, as you say, as anything less only separates individuals with autism from effective, scientifically-validated treatment.

I look forward to the second part of our interview where you respond to questions such as:

• What should behavior analysis organizations do to better address this issue? In your view, what are they not doing?

• What are some suggestions you would make to behavior analysts working on multi-disciplinary teams?

• What are the three most important things needed to bolster a shared commitment to science and to attenuate the influence of pseudoscience?

• Can you provide our readers with some specific homework? What titles would be good reads and why?

The conclusion of this interview will appear in the Summer Issue of Science in Autism Treatment.

References


James T. Todd, Ph.D. is Professor of Psychology at Eastern Michigan University. He earned his Ph.D. in Human Development and Child Psychology in 1990 at the University of Kansas studying under Edward K. Morris. Morris instilled in Todd a deep respect for the importance of applying high-quality scholarship and science to all questions in all areas. Prior to earning his Ph.D., he spent seven years as an engineer at KANU radio, the University of Kansas Public Radio Station, and taught electronics, mathematics, and computer programming at Kansas City Area Vocational Technical School and General Motors. At Eastern, he has taught courses on a variety of topics including, "Everyday Computing and Social Responsibility," the "Experimental Analysis of Behavior," and "Clinical Ecological Psychology." From 1999 to 2003, Todd served as Psychology Department Head and then Association Dean of the College of Arts and Sciences. It was while Todd was Psychology department head that Eastern Michigan approved the first Ph.D. program in its history (in Clinical Psychology)—although Todd points out that the real credit for the development and success of the program belongs to others. He is co-editor, with Ed Morris, Modern Perspectives on John B. Watson and Classical Behaviorism and Modern Perspectives on B.F. Skinner and Contemporary Behaviorism, published on the history of behavior analysis, schedule-induced behavior, and animal models of exposure therapy. Todd is also Secretary/Treasurer of the Behavior Analysis Association of Michigan (BAAM). Todd has had a longstanding interest in superstitious, magical, and pseudoscientific thinking. Lately, like many behavior analysts, he has been drawn into teaching and working in the area of autism, which has lead to serving as expert witness and consultant on several recent court cases involving the discredited intervention, facilitated communication.

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Providing Accurate, Science-Based Information - Promoting Access to Effective Treatment
Clinical Corner: Discussing Concerns with Family Members

Question: I am concerned that my grandson may have signs of autism, but I am uncomfortable bringing this up with my son and daughter-in-law. Do you have any suggestions about how best to approach them?

Answered by: Peggy Halliday, M.Ed., BCBA (Virginia Institute of Autism) and David Celiberti, Ph.D., BCBA-D (ASAT President)

It is natural to be unsure of how to share your concerns with your grandson’s parents. As is the case with many concerned family members, you may worry that such a discussion may not be well received. If autism is a possibility, you would not want to delay screening and referral for possible evaluation and services, because this may waste valuable time during which intervention can be most beneficial for your grandson. Even knowing that best outcomes are associated with early diagnosis and intensive intervention, it still may be difficult to talk to your son and daughter-in-law if they have not expressed concerns to you.

As a grandparent, you have already raised at least one child, so you probably have a good sense of what is typical in child development, and what is not. You may feel that your grandson is not making expected gains or may appear delayed in some areas such as communication or play relative to other children his age. This may create in you a sense of urgency which must be balanced with the need to support your son and daughter-in-law.

There are a number of important things to consider. The way in which you approach your son and daughter-in-law will depend in large part on the quality of your pre-existing relationship and on the nature of how you communicate with one another. You may possess a relationship where difficult issues are frequently and easily discussed. On the other hand, this may not typify the type of relationship that you have. Regardless of your relationship, it is important that you bring this up from a place of love and concern, rather than judgment and blame. Many parents who have been carefully and respectfully approached by a relative later admit that they already had concerns of their own, and it was a relief to discuss them with someone else close to the child.

We would like to offer some concrete suggestions that may increase the likelihood that your discussion will be constructive:

1. Plan your discussion ahead of time. Find a time and place when you will not be interrupted.
2. Take some time to think about what you want to share and how you want to frame your concerns. You might begin by commenting on the child’s strengths and praising the parents’ love and dedication to their child. It is important not to appear judgmental.
3. Try to keep the conversation free flowing. You may want to ask a few questions that will allow the parents to express their own concerns, if they have them (e.g., “I noticed that Billy became very upset when the phone rang. Has that happened before?” or “Does he seek you out when he is upset?”).
4. The role you take in the child’s life depends, of course, on geographic proximity, but offer concrete, practical help whenever possible. For example, you might offer to babysit siblings while parents pursue evaluation of the child, or offer a respite weekend of childcare so that your son and daughter-in-law might have time to discuss the situation without interruption. Whatever assistance you offer, the important thing is that your grandson’s parents perceive it to be helpful, so try and gauge their reactions carefully.
5. Avoid labels and technical terms, which may trigger fear or upset with the parents. Focus instead on discussing milestones, which are observable indicators of a child’s development and accomplishments.
6. In some cases, it may be beneficial to think about the discussion as a series of tiny conversations. This would be more appropriate if you have frequent contact with your son or daughter-in-law. It may then be helpful to share some observations that may provide a backdrop for later discussion (e.g., “Little Peter seems overwhelmed by noise levels” or “I have noticed that he does not seem to know how to use words to get his needs met.”). It may also be helpful to discuss observations surrounding worrisome or absent peer or sibling interaction.

(Continued on page 10)
Clinical Corner Continued

7. Emphasize the need to simply get any concerns checked out in order to “rule out” anything serious or to get some guidance in how to promote skill development. You might follow this up by mentioning that the earlier a potential problem is recognized and addressed, the easier it is to help the child.

Most parents begin to become concerned that something may be wrong when their child is between the ages of 12 and 18 months. If the parents are beginning to realize a potential problem exists, you want to gently urge them not to delay a preliminary assessment and evaluation. You should never take for granted that developmental concerns will automatically be addressed during routine visits to the pediatrician. Refer parents to resources such as books and good websites they can explore on their own (we emphasize the word “good” as there is a tremendous amount of misinformation about autism both in the media and on the Internet, particularly many false promises about autism treatment). The most helpful websites at this stage are typically the ones that discuss developmental milestones. Parents often know when to expect their infant and toddler to sit up or take their first steps, but they do not know when they should begin to babble with inflection, point to things they notice or want, imitate gestures, or show interest in another child. The following websites include milestones checklists, booklets, and charts, and a wealth of other helpful information:

**Centers for Disease Control and Prevention:** The Act Early website contains an interactive and easy-to-use milestones checklist you can create and periodically update for children ages three months through five years, tips on sharing concerns with the child’s doctor, and free materials you can order, including fact sheets, resource kits, and growth charts. [www.cdc.gov/ncbddd/actearly/index.html](http://www.cdc.gov/ncbddd/actearly/index.html)

**Autism Speaks:** The Autism Speaks website includes an Autism Spectrum Disorder Video Glossary of video clips designed to help parents and professionals learn more about the early red flags of autism, information about how autism is diagnosed, a resource library, and a free 100 Day Kit designed to help families of newly diagnosed children make the most of the first 100 days following a diagnosis of autism. [www.autismspeaks.org](http://www.autismspeaks.org)

**First Signs:** The First Signs website contains a variety of helpful resources related to recognizing the first signs of autism spectrum disorder, and the screening and referral process. There is a directory of local resources for at least eight states and we think it is likely that the number of states represented will increase over time. [www.firstsigns.org](http://www.firstsigns.org)

**American Academy of Pediatrics (AAP):** The AAP website contains information for families, links to many other web sites, information about pediatrician surveillance and screening, and early intervention. This site contains great tools for pediatricians, as well as parents. [www.medicalhomeinfo.org/health/autism.html](http://www.medicalhomeinfo.org/health/autism.html)

**Association for Science in Autism Treatment (ASAT):** On the ASAT website, you will find extensive information about the scientific support (or lack thereof) behind the full array of treatments proposed for autism, research reviews, articles and guidelines on how to make informed choices and weigh evidence in selecting treatment options, a section of frequently asked questions such as the one you asked, information about upcoming conferences of interest, and links to helpful sites and other science-based organizations.

In summary, we think it is commendable that you desire to share your concerns in a sensitive way with your son and daughter-in-law. We hope that this advice has been helpful to you, and we wish the best for your grandson’s future. In the event that your concerns are founded and your grandson receives a diagnosis of autism, we recommend that your family refer to the 100 Day Kit from Autism Speaks and learn all they can about applied behavior analysis, the treatment for autism that has the most compelling scientific support. The ASAT website of course would be an incredible resource at that point as well.
The Association for Science in Autism Treatment (ASAT) accepts advertising for the ASAT.org web site, newsletter and other ASAT publications to offset its operational expenses. Products or services accepted for advertisement by ASAT will be consistent with our mission to disseminate accurate, scientifically-sound information about autism and its treatment 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.

All advertisers must sign the ASAT Advertising Application. ASAT maintains the right to refuse any proposed advertisement that is incompatible with its mission, as determined through a case-by-case review by the ASAT Board of Directors, prior to placement of advertisement in ASAT publications.

In order to be considered for acceptance by the ASAT Board of Directors, the proposed advertisement must NOT:

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- suggest endorsement by ASAT;
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- collect personal information from an individual visiting www.ASAT.org; or
- use cookies, applets or other such files that transmit or otherwise collect personally identifiable information.

For each possible ASAT advertiser, an authorized person will be required to sign off that his/her organization is in support of the following tenets:

1. All treatments for individuals with autism should be guided by the best available scientific information.
2. Service providers have a responsibility to rely on treatments that have been shown to be safe and effective in scientifically rigorous, peer-reviewed research studies.
3. Service providers should take steps necessary to help consumers differentiate between scientifically-validated treatments and treatments that lack validation.
4. Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.
5. Objective data should be used when making clinical decisions.

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Please ensure that your ad does not make unsubstantiated health or treatment claims, suggest endorsement by ASAT, or contain religious or political content.

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ASAT
Providing Accurate, Science-Based Information - Promoting Access to Effective Treatment

Reviewed by Josh Pritchard, MS BCBA, Member of ASAT’s Board of Directors

Blessed with Autism by Christina Peck is a guide for parents on how to secure funding for the treatment of their child. I am sharing this book review as it is consistent with the second part of ASAT’s mission: “to improve access to effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.” With so many variations of insurance, state support, and educational requirements, it seems difficult for someone to write a single book that would be of much help to parents from diverse regions across the country. However, Peck was able to maintain the fine balance between keeping her instructions, tips, and examples broad enough to be helpful across a multitude of locales while also being specific and detailed enough to be usable. It is my hope that from this book will stem a research line that delineates the most effective empirically-supported approach to effective advocacy. This review will provide the reader with a glimpse of the contents of Peck’s book while pointing out some salient components that set it apart from others.

Peck walks the reader through her personal experience with her firstborn, Sami. From the beginning of her contractions, the delivery and APGAR tests, to the first several signs that her daughter had autism, Peck demonstrated the required persistence by describing the efforts (a full day) just to schedule a developmental pediatric appointment. This chapter sets the tone for the rest of the book.

The second chapter begins with the words many parents dread - and the horror with which they are associated. It paints a very real picture of the anguish felt as her words unfold, even to a reader who has not been in this situation. However, Peck doesn’t wallow in self-pity; rather, she indicates the actions one must immediately take: the first step-find a private consultant. This might have been a good opportunity to espouse the characteristics of a consultant for which parents should be looking, but as the chapter progresses, the consultant’s techniques become clearer. While Peck failed to specifically name behavior analysis (ABA), she did describe some of the programs she utilized with ABA-based treatment, and made the astute observation that it is now part of how she routinely parents. This way-of-life mentality is incredibly important to the well-being of the children. As she continues to describe the various therapies provided, she makes the point that although hiring therapists is important (and also gives tips on where and how to find good potential consultants), they are the parents who must become the child’s “protectors, advocates, and the best therapists he or she will ever have.”

This chapter begins to demonstrate Peck’s ingenuity and methodical planning and execution in acquiring appropriate treatment for her daughter. Her first interaction with the state early intervention treatment team is detailed and allows readers to view, firsthand, the intensity, determination, and assertive qualities required to effectively advocate for their child. After this initial interaction, Peck demonstrated that often a firm, yet pleasant and polite advocate can develop a respectful, effective, long-lasting and pleasant relationship with case managers and others with whom they must advocate for their child.

As Chapter 3 begins, the reader gains insight into Sami’s life and progress. They can see what effective advocacy can do to help a child with state funding and educational support. Until this point, there had been no mention of insurance, so when Peck’s husband mentioned it a bit off-handedly, she called the insurance company the next morning. During this call, she discovered something that makes this book invaluable. It is here that Peck begins to unravel the deviously intertwined system of insurance codes, rules, and regulations. She found that autism would not be covered if billed as such, but that often, the same services can be covered under different diagnoses. In their case, speech therapy was covered if due to ear infections and apraxia. She discovered the flexibility of insurance companies as they allowed her to increase the 30 approved visits of speech therapy by 110 sessions. Becoming knowledgeable about insurance coding can help to relieve some of the financial burden for families (many of whom have already made significant sacrifices) and allow them to focus on effective, uninterrupted treatment for their loved ones.

The power of Peck’s recommendations and systematic approach to funding is that she never recommends reliance on a single funding source. In Chapter 4, the reader is introduced to the public school system and given the same detailed steps for success when dealing with this entity. She includes her letters to the director of special education as well as an itemized list of non-negotiable services requested for the first year of Sami’s school career. At this point, Peck has provided a parent with enough knowledge, examples, and tips to help secure (funded)

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Peck continues to share jewel after jewel as she describes how she quickly wrote some thank-you letters, but then dove head first into the third IEP meeting requests, summaries, and reports. With all of the hassle of these meetings, the rigorous schedules required, and Peck’s sacrifice of her own social life, some readers might ask, “why not stop and bask in her glorious success?” Peck wisely points out that although she was elated; this was not a time to become complacent. If she had stopped there, Sami might not be where she is today, and more importantly to the reader, this book probably would not have been written. She concludes by describing her daughter’s amazing progress and status and the immense love she feels toward her.

Chapters 10 and 11 are workbooks that walk the parent step-by-step through the process of interacting with their insurance company. Complete with sample letters, invoices, and more tips and tricks, these chapters provide a reference guide, enabling novices to immediately begin advocating for their child, to prepare adequately for interactions regarding reimbursement and funding. These chapters also provide a quick-and-dirty explanation of the confusing world of insurance codes. Parents who follow the steps outlined in these chapters will find themselves with an amazingly comprehensive record of all they’ve done, as well as a higher likelihood of successful funding.

In the final chapter before the workbooks began, Peck revealed that she was struggling with the idea that her youngest might also be on the spectrum. It is at that moment when the extraordinary value of this book becomes evident. Through her journey, Peck developed the confidence and ability to stare this daunting diagnosis in the face, and learn about herself that she has the wherewithal to not only cope with autism, but actively treat the symptoms and problems with which it is associated. She admits that her road is not over, but assures the reader that it is “has been repaved and is much smoother.” To parents questioning their ability, this could be music to their ears. The message is loud and clear – it will not always be fun – but with the right approach, lots of time and effort, parents can gain the confidence and ability to not only advocate, but actively help their child reach his or her potential. When reading this book, one can feel the elation and glow of a hard-earned success and the satisfaction of knowing that Sami was blessed to have such tenacious parents.

In conclusion, Blessed with Autism provides parents (or any other advocates) a delightful read, as well as a treasure trove of resources for the organization and systematized execution of a battle plan to secure funding for the treatment of one’s child. Readers might easily find themselves turning the final page, with goose bumps wondering how Peck was able to pack so much information and organization into a book that simultaneously had the ability to warm their hearts and bring hope and direction to their current situation.
Maine Dairy Queen Owners Lend a Hand to Support ASAT
By Betsy Dyer, M.A., CCC-SLP

The Board of Directors of ASAT wishes to acknowledge and thank Larry and Kathy Hannon, owners of Dairy Queen stores at the Bangor Mall in Bangor, Maine and in Old Town, Maine.

The Hannon’s recently made a $500 donation to ASAT and, through the generous support of Dairy Queen customers, have raised over $600 with donation jars placed on their counters and at their drive-thru window! In addition to passing out hundreds of business cards showcasing ASAT’s website, they have some unique and exciting plans to spotlight ASAT during April’s Autism Awareness Month.

For those of you in Maine, please visit either or both of their stores for some delicious treats and to see how their continued fundraising efforts are coming along. Stay tuned for a more in-depth piece on this wonderfully supportive and dedicated team from Maine which will appear in an upcoming newsletter.

Thanks to Larry, Kathy, and the entire Dairy Queen crew for their dedication to and support of ASAT!

Position Statement Published by American Academy of Pediatrics by Tristram Smith, Ph.D.

Vision Therapy is not an evidence-based intervention for children with learning difficulties, according to a recent position statement from the American Academy of Pediatrics: "There is no scientific evidence to support the use of eye exercises, vision therapy, tinted lenses or filters to directly or indirectly treat learning disabilities, and such therapies are not recommended or endorsed. There is no valid evidence that children participating in vision therapy are more responsive to educational instruction than children who do not participate."

For more, see http://www.aap.org/advocacy/releases/july2709vision.htm.

Also, check out Vision Therapy on the ASAT website: http://www.asatonline.org/intervention/treatments/vision.htm
Consumer Corner: Resources for Implementation of Evidence-Based Practice
by Kate Fiske, Ph.D., BCBA-D

Though many parents and professionals recognize the importance of implementing evidence-based practices for children with autism, they may struggle with identifying resources that offer practical strategies for implementing these practices. The National Professional Development Center (NPDC) on Autism Spectrum Disorders (ASD) has compiled a series of briefs on 24 evidence-based practice approaches for individuals with autism, including: antecedent-based interventions, differential reinforcement, discrete trial training, extinction, functional behavior assessment, peer-mediated instruction, pivotal response training, Picture Exchange Communication System (PECS), Pivotal Response Training (PRT), prompting, self-management, task analysis, video modeling and others. The briefs for these practices can be found at the following address: http://autismpdc.fpg.unc.edu/content/briefs

The NPDC’s briefs are well-organized and user-friendly, with a “package” of PDF files available for each approach. Each package includes a summary of the evidence base for the practice, an overview of the approach, a detailed description of the steps required for implementation, and a checklist of necessary implementation steps. Additionally, several briefs include related data sheet templates and sample data sheets pre-filled with fictitious data to illustrate their use.

One of the strengths of the compilation of briefs is the heavy emphasis on the assessment and treatment of problem behavior. Several briefs—functional assessment, extinction, differential reinforcement, functional communication training, and antecedent-based interventions—describe best practices for identifying the function of a behavior, and designing and implementing a function-based treatment for the behavior. For many professionals and parents, the area of functional assessment will be one of the most helpful, especially given the frequent necessity for implementing functional behavioral assessment in response to problem behavior in home and school settings. The step-by-step instructions for conducting a functional assessment and implementing function-based treatment—accompanied by a very helpful checklist to ensure that all steps are completed—will be valuable to any professional conducting the assessment, or to any parent who wishes to ensure that a functional assessment and treatment are implemented appropriately. Importantly, the authors point out that some treatment practices, such as extinction, can be very effective but should only be used in conjunction with other strategies, such as functional communication training and other antecedent-based strategies. Such cautionary statements are invaluable when professionals are using these briefs as references for designing an effective behavioral intervention.

The NPDC should also be praised for its emphasis on the importance of data collection for all procedures included in their briefs list, as is evidenced most obviously by their inclusion of data sheet templates in many briefs. The group repeatedly states that baseline data should be collected on a skill or problem behavior prior to the implementation of an evidence-based practice, and then monitored over time to ensure that appropriate changes in behavior are observed. Furthermore, the group attends nicely to considering setting and context when implementing interventions. For example, one brief on “parent intervention” cautions the professional to be aware of family environment when designing interventions for the home. Additionally, when considering best practices for peer involvement in intervention, the authors establish different steps to intervention based on the educational level of the students (early childhood, middle school, high school) to help professionals adapt to the developmental needs of these age groups. These sensitivities are highly important when treating individuals with autism, but may be often overlooked by professionals.

In addition to these briefs, the NPDC has also begun to compile a list of Autism Internet Modules, hosted by the Ohio Center for Autism and Low Incidence (OCALI) at http://autismpdc.fpg.unc.edu/content/autism-internet-modules-aim. These modules can be accessed after setting up a free account with OCALI, and include topics related to the evidence-based practices reviewed in the briefs (e.g., PECS, PRT), but also extend to topics such as the assessment and...
### Continued: Resources for Implementation of Evidence Based Practice

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diagnosis of autism. The modules include written text as well as pictures and video related to each topic. Many modules included on this website are listed as “coming soon,” so this site will likely be a growing resource in years to come.

Frequently, the briefs listed on the NPDC site are stamped with the word “draft,” indicating that the briefs are a work in progress. These documents will undoubtedly change over time, and may be added to as further evidence is found for current and future treatments. One also hopes that the NPDC will expand upon current topics by offering an elaborated description of variations of the procedures addressed. For example, in describing methods by which to identify student preferences, only one example of a reinforcer sampling is offered (Mason & Egel, 1995). Other assessments (e.g., DeLeon & Iwata, 1996; Fisher et al., 1992) offer valuable information about a student’s preferences and may be beneficial to include in the brief. Synthesizing different bodies of research that describe variations of similar evidence-based practices (e.g., preference assessments, discrete trial instruction) is a challenge, but ultimately will be beneficial for consumers.

In sum, the NPDC has created an approachable resource for consumers that provides clear descriptions of frequently used evidence-based practices. Particularly helpful for professionals working in public schools, the implementation steps and checklists for each practice will be an excellent resource for those wishing to implement practices with integrity. Additionally, several briefs offer a concise summary of broad topics (e.g., PECS) that can be used as a handy reference to supplement other program materials and guides. The continued development of the briefs and modules will be a wonderful resource by which professionals and parents can identify best practices, as well as the steps required to implement them.

### References


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Parents,

I am a part of a group of researchers conducting a survey to evaluate parents’ opinions of the National Research Council’s (2001) recommendations regarding the education of children with autism. Your responses will provide valuable information on how parents feel these recommendations have been implemented. The survey will take about 15 minutes of your time to complete, and your responses are confidential and anonymous. If you wish to complete the survey, please click on the link below.

http://www.zoomerang.com/Survey/WEB22A54PEWUHN

Thanks,

Matt Tincani, Ph.D., BCBA-D
Temple University
Autism is a complex disorder characterized by significant deficits in social reciprocity and communicative ability as well as the presence of repetitive behavior/restricted interests. Given the heterogeneous nature of autism, many interventions have emerged with claims of effectiveness. Applied Behavior Analysis (ABA), sensory integration, specialized diets (e.g., gluten and/or casein free diets), pharmaceutical interventions (e.g., Risperdal), and mercury detoxification procedures are among the most commonly-used interventions with learners on the autism spectrum. However, with the exception of ABA, many of these treatments persist in the absence of scientific data supporting their use. This absence of data is particularly problematic for parents and practitioners who are trying to provide the best possible intervention for their learners with autism. The prospect of selecting an appropriate treatment for autism can be overwhelming for anyone with the vast amount of conflicting information available.

Most experts agree that the best first line of treatment is an intensive, coordinated program of special education and behavior management. Developmentally appropriate intervention programs generally include a language-based curriculum, systematic intervention to improve communication and social skills and a structured plan to address maladaptive behavior. Behavioral intervention strategies, derived from ABA, have the most empirical support for their use. In addition, ABA has been endorsed by the U.S. Surgeon General (1999), National Institutes of Health (NIH) and the National Standards Report published by the National Autism Center (2009).

Non-behavioral treatments can generally be divided into two main categories: biological and non-biological interventions. Biological interventions include treatments such as Hyperbaric Oxygen Therapy (HbOT), vitamin therapy, specialized diets (e.g., gluten-casein free diets, Feingold diet) and psychotropic medication. With the exception of psychotropic medication research, sound empirical evidence supporting the effectiveness of these interventions for learners with autism is sparse.

Of note, several studies have shown that certain psychotropic medications (e.g., Risperdal) can decrease some aberrant behavior (e.g., impulsivity, aggression). Non-biological interventions include treatments such as Sensory Integration Therapy (SIT), Facilitated Communication and Craniosacral Therapy.

While behavioral intervention is a good, empirically-supported starting point, it would not necessarily preclude the use of alternative interventions, if the use of such alternative interventions was carried out in a careful manner using operational definitions of targets, continuous data collection and a strong design to assess efficacy. Rejecting other types of intervention without understanding and evaluating them is problematic for several reasons. First, the absence of supporting evidence is not the same as evidence against an intervention. One of the main problems with the new and emerging treatments for autism is that limited research has been done to either validate or invalidate these interventions. Complicating this further is the fact that scientific journals do not typically publish negative research findings. In other words, research indicating that particular treatments are not effective may not be accepted for publication because of a journal’s bias to only print positive findings.

Another complicating factor is the individual variability of response to different treatments for autism. As mentioned previously, autism is a complex disorder with a variety of different etiologies that may affect response to treatment. Strategies may work for some learners and not others. It is important for practitioners to approach the intervention process with an objective mind. Rather than dismissing alternative approaches to intervention, practitioners should take the opportunity to study these interventions and systematically eliminate components that are not effective. Unfortunately, alternative interventions are often carried out in an unsystematic manner which precludes a valid assessment of outcome.

Alternative therapies are going to be part of the autism treatment landscape for years to come. It is the responsibility of both parents and practitioners to become informed consumers of autism services. It is important to critically review the validity of proposed treatments, read the literature (peer-reviewed articles rather than testimonials or anecdotal reports) and look for scientific evidence of benefit, potential health risk, and financial or time cost of all treatments. While the temptation to “leave no stone unturned” may seem appealing, wasting precious time with ineffective interventions may prevent learners from maximizing their potential.

In addition to educating themselves about alternative interventions, practitioners and parents should critically evaluate the effectiveness of the intervention process. It is often the case that people do not use systematic designs to assess the effectiveness of alternative treatments. Implementing treatments in a

(Continued on page 18)
reversal (ABAB) design or multi-element designs can provide valuable information regarding the efficacy of treatments. Furthermore, a variety of behavioral assessment and measurement procedures, such as observational data coding, preference and reinforcer assessments, and functional analyses, can be viable ways to evaluate the effects of these interventions. Using behavioral measures for the purpose of evaluation can allow for testing some of these alternative interventions to determine if there is a clinically-significant response. Such procedures could allow parents and practitioners to only use interventions that are effective and discontinue components that are ineffective. These measures can be used to determine if treatment effects generalize to different settings and also to monitor the occurrence of side effects.

In summary, there exists a wide variety of behavioral and non-behavioral interventions for learners on the autism spectrum. Some of these interventions have garnered empirical support (i.e., ABA and some psychotropic medications) while many have not been studied thoroughly enough to validate the effectiveness for use with learners with autism. Unfortunately, many treatments that are ineffective persist because they often promise miraculous results and are easy to use. The best solution is for parents and practitioners to educate themselves regarding these alternative therapies and critically evaluate the effectiveness of these interventions. In doing so, parents and practitioners can ensure the best possible intervention for their learners, prevent time from being wasted and can ultimately help others through the process by sharing their findings with others.

Toward this end, I will outline five ways that you can help us reach the goal of spreading the scientific information by doubling our subscription base before the end of 2010. Let us begin with you—if you are not already a subscriber, take a moment to do so at: http://www.asatonline.org/signup

First, feel free to forward the newsletter e-mail to anyone that you think might benefit from the information in each issue. There is a link in the e-mail you received (if you are already a subscriber). Simply click this link and then fill in your name, email and your friend’s e-mail, we’ll handle the rest.

Second, become a fan on Facebook by clicking: http://www.facebook.com/#/pages/Association-for-Science-in-Autism-Treatment/72449733735 Once you are a fan, post to your wall suggesting that others become a fan and provide the signup link (listed above). You can post on your wall as we announce dates for upcoming newsletters. Once you’re an ASAT fan, we’ll post important news, events, and dates for your convenience.

Third, tweet about us! New to Twitter? Click here for a quick video tutorial on how to get started. If you haven’t heard of Twitter, here’s a fun introduction to it. Once you’re signed up, you can send several types of tweets, for instance:

- A specific article you read in the newsletter that you liked!
- A link to our sign-up page with your goal for subscribers.
- A tweet about upcoming newsletter releases.

As usual, it has been a great honor working with all of our contributors and my co-editor, David. As we put together the pages of this spring issue, we quickly realized that our newsletter was bursting at the seams!

Consequently, we split a few of our articles into several parts, and are expecting an equally packed summer issue. For example, two exciting articles in the upcoming summer issue to which you can look forward:

- Part two of the featured interview with Dr. James Todd
- A discussion of New Jersey’s insurance laws as an example of how to get insurance funding
- Update on the flurry of activity from our Media Watch team

While our newsletter is driven entirely by volunteer man-hours and the passion of people who believe that everyone affected by autism should have the benefit of science on their side, we can sure use your help!
Does your agency share ASAT’s values?

ASAT believes that individuals with autism have the right to effective treatments that are scientifically demonstrated to make meaningful, positive change in their lives.

We believe that it should not be so challenging for families to find accurate information about the efficacy of various interventions for autism.

ASAT works toward a time when:

…………all families would be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.

…………the media would educate and not confuse parents by providing accurate information and asking the right questions.

…………all providers would be guided by science when selecting and implementing their interventions.

Help us work toward this goal.

What it means to be a sponsor…..

ASAT’s sponsors have indicated their support of the following tenets:

1. All treatments for individuals with autism should be guided by the best available scientific information.

2. Service providers have a responsibility to rely on science-based treatments.

3. Service providers should take steps necessary to help consumers differentiate between scientifically-validated treatments and treatments that lack validation.

4. Consumers should be informed that any treatment lacking scientific support should be pursued with great caution.

5. Objective data should be used when making clinical decisions.

These Sponsorships not only provide financial support used specifically for our dissemination efforts, but also send a clear message that ASAT’s vision is shared by others within the professional community.

…..Become a 2010 Sponsor

The tasks of educating the public about scientifically-validated intervention and countering pseudoscience are daunting ones, and ASAT appreciates the support of all of its sponsors.

In 2009, the organizations listed below had indicated their support for ASAT and its mission. Thus far, a few new organizations have joined our 2010 campaign and most of our 2009 Sponsors are renewing.

If you are interested in becoming a 2010 Sponsor, please visit the sponsor page on our website at www.asatonline.org/about_asat/sponsors.htm#learn

Thank you for your consideration!

Last Year’s Sponsors in Real Science, Real Hope

CHAMPION $2,000
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Connecticut Center for Child Development (CCCD)
Educational Partnership for Instructing Children (EPIC)
Evergreen Center
Institute for Educational Planning
Lizard Children’s Learning Centre
Reed Academy
Room to Grow
SKF Books
Somerset Hills Learning Institute

IMPORTANT DISCLAIMER: ASAT has no formal relationship with any of the sponsor organizations. Furthermore, their stated endorsement of the above tenets is not verified or monitored by ASAT. Although ASAT expects that all sponsoring organizations will act in accordance with the above statements, ASAT does not assume responsibility for ensuring that sponsoring organizations engage in behavior that is consistently congruent with the statements above.

ASAT

Providing Accurate, Science-Based Information - Promoting Access to Effective Treatment
Fourth, share our newsletter sign-up fliers with locations that are frequented by those who could benefit from the information that we provide. You can find this announcement by going to our page: http://asatonline.org/pdf/newsletter_ad.pdf

Finally, you can send a personalized e-mail to anyone that could benefit from our newsletter. When you do this, we suggest that you include a description of a few of the features that you've really found helpful or interesting. Attach the latest edition or include a link to our archive section: http://asatonline.org/newsletters/archives.htm

I hope these five suggestions have provided you with the tools you can use to help us reach our goal. Each issue will include a goal-o-meter to help identify where we are with respect to our goal to double the number of subscribers.

Remember, just because someone is knowledgeable about science-based treatment, they may not know about the Association for Science in Autism Treatment. We hope that folks sharing SIAT with others will discover new friends and other people who have knowledge to share based on science.

Ask yourself—how many people do I know that could benefit from the information on science based treatment for autism? I suggest the answer is simply the number of people you know.

We appreciate all that you do to help us bring you the best information available.

Yours in Science,

Josh Pritchard, MS, BCBA
Co-editor of SIAT

In addition to our entire board of directors, we acknowledge the following 2009 donors. Without their support, our important work could not be carried out.

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Joint attention occurs when two people share attention with an event or object. Deficits in joint attention are among the earliest indicators of autism and these deficits have been associated with difficulties in subsequent language development and social skills. Interventions to increase joint attention, therefore, may be helpful in increasing communication and social skills for children with autism. These articles outline several different strategies to teach joint attention.

Sharon A. Reeve, Ph.D., BCBA-D, SIAT Research Corner Coordinator
Joint attention occurs when two people share a focus on objects or events in the environment. Typically developing children both initiate and respond to joint attention by the time they are about 9 months old, and this skill helps them learn to communicate back and forth with another person. In contrast, young children with autism seldom display joint attention—a problem that hinders them from learning to communicate. Therefore, interventions to improve joint attention may be a priority in early intervention programs for these children.

What did the researcher do?

The authors tested an intervention that had two components: a structured teaching format called discrete trial instruction (DTI) and a format for teaching during naturally occurring activities called pivotal response training (PRT). Participants were five preschoolers with autism. All participants entered the study at the same time and were observed for several days before any of them received intervention. Then the start of the intervention was staggered across children to find out whether the intervention increased children’s responding to and initiating joint attention regardless of when it began. Later, parents of two of the five children were trained to implement DTI and PRT for joint attention at home and in the community, and these parents were asked about changes in their child’s language and social behavior following intervention.

What did the researchers find?

The intervention increased joint attention at school and with parents at home and in the community. According to parents, the quantity and quality of their child’s interactions improved, and their child appeared happier.

What are the strengths and limitations of the study?

The success of the intervention suggests it is possible to address core deficits of autism such as joint attention by systematically teaching specific skills with behavioral interventions. In addition, joint attention may be a pivotal skill that can lead to improvements in other important areas, such as expressive language and social communication. Future research needs to involve larger groups of students and more careful assessment of collateral changes in domains such as plan and language acquisition.

What are the strengths and limitations of the study?

The current investigation highlighted the potential benefits of targeting joint attention in interventions for individuals on the autism spectrum. To help maintain and extend skills, it may be important to train parents to implement the treatment. Limitations of the study include the implementation of all procedures in a laboratory rather than “real world” settings, reliance on reinforcement (access to preferred toys) that is unlike the reinforcement that typically developing children receive for joint attention, and the limited range of joint attention behaviors that were taught (responding to and initiating eye gaze, but not other types of communication such as showing objects).
**Treatment Summary: Developmental Therapies by Tristram Smith, Ph.D.**

**Description:** Developmental therapies, also called social-pragmatic interventions, are intended to promote social communication and other social interactions. The therapist or parent aims to make highly motivating activities available to the child, be responsive to what the child does (e.g., imitating or commenting on actions that the child performs) and encourage ongoing interaction around these activities (e.g., turn-taking, requests, gestures, or alternation of gaze between the activity and the adult).

**Examples:** Denver Model, Responsive Prelinguistic Milieu Teaching (RPMT), Social Communication, Emotional Regulation, and Transactional Support (SCERTS). See also the sections on Developmentally-based Individual-different Relationship-based (DIR) intervention and Relationship Development Intervention.

**Research Summary:** Developmental therapies are widely considered to be plausible intervention approaches (National Research Council, 2006). However, only a few studies have tested these interventions. In a small but well-designed study of preschool children with autism, Yoder and Stone (2006) found strengths and weaknesses of a developmental approach (RPMT) relative to an applied behavior analytic approach (Picture Exchange Communication System; see the sections on applied behavior analysis and on the Picture Exchange Communication System). RPMT was more effective than PECS for promoting turn-taking and joint attention (alternation of gaze between an activity and an adult); however, PECS was more effective than RPMT for increasing vocabulary size and frequency of communication.

In an important, well-designed study, Dawson et al. (2010) evaluated the Denver Model, which mixes developmental approaches with applied behavior analytic interventions (especially Pivotal Response Treatment). Twenty-four children who were 18-30 months old when they entered the study and who received two years of services based on the Denver Model were compared to a control group of 24 similar children who received services in their communities. Following intervention, children in the Denver Model obtained significantly higher scores on tests of IQ and adaptive behavior, and displayed significantly fewer autistic behaviors, than children who received community services.

**Recommendations:** Developmental therapies are an under-researched intervention approach. An important area for future research is to evaluate developmental therapies in studies with strong experimental designs. Professionals should present developmental therapies as under-researched and encourage families who are considering these approaches to evaluate them carefully.

**Selected References:**

*Systematic reviews of scientific studies:*


*Selected scientific studies:*


Join our Facebook Fan Page! Please invite your Facebook friends to join as well.

With your help, we are reaching out to more people every day united in their commitment to science in the treatment of autism. Individuals with autism deserve nothing less! Posts on our fan page include:

- Information about upcoming issues of our newsletter, Science in Autism Treatment
- Media Watch announcements
- Other ASAT News and Highlights

We now have 1024 fans on ASAT’s Facebook. Are you one of them?

If not — become one now; click on the logo to the right.

We will showcase our 2000th fan in an upcoming issue ……with his/her consent of course!
Message from ASAT President, David Celiberti, Ph.D., BCBA-D continued ....

(Continued from page 1)

Although these values should influence and guide all that we do when helping individuals with autism realize their fullest potential, sadly, this is not always the case.

In contrast to other autism organizations, ASAT’s sole purpose is to share accurate, science-based information about autism treatment. ASAT continues to do all it can to carry out its mission and work toward the various goals delineated in the Winter 2010 issue. One of those goals is to distribute four comprehensive, information-packed issues of Science in Autism Treatment (SIAT) per year. Josh and I are proud to present to you this Spring 2010 issue.

To those of you who view Autism Awareness Month as a gentle reminder to support the autism organizations that share your values, I ask you to give ASAT your fullest consideration. We are a small and frugal organization with no paid staff or office overhead. To put things in perspective, ASAT’s annual budget is a tiny fraction of other organizations, such as Autism Speaks. Your financial support, however small, can make a big difference and is always appreciated. There are many ways to help:

- Please help us increase awareness of our website and newsletter by sharing information with colleagues and other families. Josh speaks about this in his letter on page 18.
- Please make a donation by completing the donor panel on page 23 or donating online through Pay Pal (found on the lower left corner of our home page at www.asatonline.org). We are so grateful for the 2009 donors listed on page 20.
- If you are affiliated with a professional organization that shares ASAT’s values, I invite you to consider becoming a 2010 Real Science, Real Hope Sponsor. Last year, 20 organizations became sponsors and our goal is to be even more successful in obtaining sponsorships in 2010. Please see page 19 for more information.
- If you are a business owner (or know of one) and would like to become a Community Sponsor or help raise monies for ASAT through donation jars or customer appeals, please write us at donate@asatonline.org. We can provide you with information about how your business can take small easy steps to support ASAT. I call your attention to page 14 where you can read about the generous efforts of the Hannon’s from the Old Town, Maine area.

Finally, I leave you ASAT’s Guiding Values and some words of wisdom from Daniel Patrick Moynihan.

Thank you all!

David Celiberti, Ph.D., BCBA-D

ASAT’s Guiding Values

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.

“You are entitled to your own opinions, but not your own facts.”

Late Senator Daniel Patrick Moynihan (1927-2003)