



Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

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Letter from Dr. David Celiberti, ASAT Executive Director

It is with deep gratitude and pride that I share with our subscribers this issue of *Science in Autism Treatment*, which feature an interview with Dr. Catherine Maurice, author of *Let Me Hear Your Voice*, and editor of two important manuals related to autism treatment. As many of you are aware, Dr. Maurice was a founder of ASAT and a longtime supporter of our efforts. We would not be where we are today without her insights, fortitude, and guidance. As a testament to the transformational impact of Dr. Maurice's writing, you can read about a young man who benefited from intensive early intervention and has resolved to give back to his community on page 43. In a related vein, we share the store of Vaughn Battista a middle school student who recently raised money on our behalf. In honor of Bullying Prevention month, we wanted to provide our readers with installments of Clinical Corner on page 18 and Consumer Corner on page 23, dedicated to this important issue. But please be sure to peruse the entire issue of this newsletter as there is so much more!

And as 2015 draws to an end, we have the opportunity to reflect on our recent accomplishments. I would like to highlight some of them below. ASAT has:

- Produced three Public Service Announcements related to ASAT, our resources, and best practices.
- Created posters conveying ASAT's mission and values.
- Held the 5th Annual Rock'n 4 Autism Awareness campaign. This effort was a huge success with over fifty businesses lending their support and raising \$10,000 dollars to promote autism awareness on both the national and local levels.
- Expanded upon our new comprehensive website with special pages for medical professionals and members of the media.
- Published numerous Media Watch letters in response to news articles and broadcasts related to autism treatment.
- Graduated several Externs, many of whom have assumed Coordinator level roles within the organization.

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- Welcomed several new committed members to the Board of Directors, from the US and Canada.
- Increased our use of social media to reach families and professionals (e.g., Twitter, Facebook, YouTube) and garnered almost 9,400 Facebook “Likes”!
- Met our goal of having subscribers from at least 100 countries.
- Presently have 1,180 followers on Twitter.
- Created an extensive database to enable us to provide information regarding ASAT and science in autism treatment to ABA faculty worldwide.
- Published four issues of *Science in Autism Treatment*, content-packed with topics of interest to families and professionals, and launched a new column called Perspectives.
- Developed a free resource booklet for parents of newly diagnosed children with autism to be distributed in 2016.

We will share our goals for next year in the Winter 2016 issue of *Science in Autism Treatment*. I would also like to take this opportunity to thank our volunteer board, externs, and committee volunteers for all of the work they do on behalf of ASAT. They do it because they believe in ASAT and want to further ASAT’s mission. I hope that you too will consider supporting ASAT. When selecting possible recipients of your year-end donations, I ask that you please give ASAT your fullest consideration.

Donations to ASAT help us to continue the important work that we do. By contributing to ASAT, you will increase the likelihood that the thousands of families with newly-diagnosed children, as well as the professionals that serve those children, will have access to clear, accurate and science-based information about autism and autism treatments. Please support ASAT at www.asatonline.org/donate/.



David Celiberti, Ph.D., BCBA-D

ASAT Executive Director

INTERVIEW

**With Catherine Maurice, PhD, Parent, Author, and
Founding Board Member of the Association for Science in Autism Treatment**

Conducted by David Celiberti, PhD, BCBA-D, ASAT Executive Director

I had the opportunity to interview Dr. Catherine Maurice, a founding member of ASAT and current member of our Professional Advisory Board. Dr. Maurice has been a long-term supporter and integral part of ASAT's success. We are deeply grateful for her support and excited to share her thoughts with you.

**David Celiberti, PhD, BCBA-D
Executive Director**

David Celiberti: Looking back at some of your work such as *Let Me Hear Your Voice*, *Behavioral Intervention for Young Children with Autism*, and *Making a Difference*: which do you think had the greatest impact?

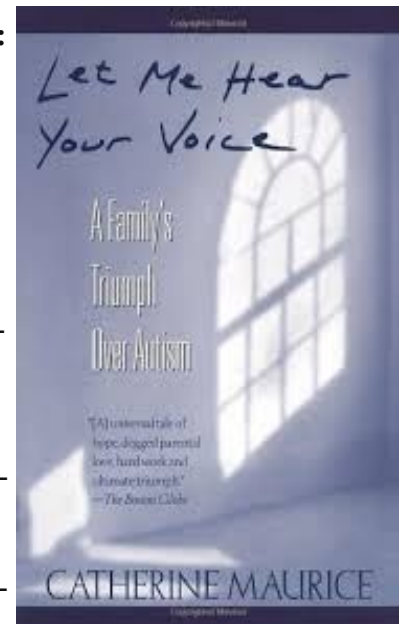
Catherine Maurice: In terms of sales, there is no doubt that *Let Me Hear Your Voice* has had a wider readership. That book was published initially by Knopf in 1993, came out in paperback within a year, then was translated into several foreign languages and is still appearing in different countries today. Most recently I signed a contract for publication in China. The two manuals you mention, written in collaboration with professionals and parents, were published through a more specialized educational publishing house, and their readership has been smaller, although I was told that *Behavioral Intervention* was for a time Pro-Ed's best selling work. Other than sales and foreign rights and that type of data, however, it's hard to evaluate impact: All books go out into the world and they can be a best seller in their field for a while, then fade away. Others never reach any kind of blockbuster status but can still ripple outward, changing minds, hearts, and policies. I don't know if it is up to me to evaluate what kind of impact my writing has had. I can talk about what I set out to do, but any assessment of my work is best left to time and others.

David Celiberti: Fair enough. What did you set out to do?

Catherine Maurice:

I guess I decided to write *Let Me Hear Your Voice* because there was so much that was wrong. In the late 1980's diagnosis was a struggle, theories about causation were mired in nonsense, and there was little help available. Obtaining reliable, science-based information about treatment was a challenge, to put it mildly.

The people who were supposed to be "advocates" for children with autism were often useless. I remember receiving a newsletter from the Autism Society of America, replete with advertisements for every snake oil lotion and potion out there at the time. There was absolutely no guidance about the scientific credibility, or lack thereof, of any of these treatments. The MDs and



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the PhDs I consulted at prestigious hospitals and universities, for their part, had no help to offer. For them, autism was a lifelong, intractable condition and the best they could offer was maybe a support group. And when I did find out about some emerging research out of UCLA, a pioneering study of children treated through ABA (Applied Behavior Analysis) authored by Ivar Lovaas, PhD, I was informed by several of these experts that ABA was dangerous and inhumane “dog training;” that it was “morally objectionable” and that Dr. Lovaas’ work was not to be given any credence.

potential for self expression and self direction was what was important to me, not taking sides in any professional or political dispute over causes or treatments for autism. But it was precisely because I saw how much my children were helped or not by various practices that I wanted to speak out about our experience.

I also wanted to show our mistakes, confusion, and consternation, and how we had to keep finding our own path toward truth. After trying this and trying that, and believing this and rejecting that, it became manifestly clear that ABA was the major catalyst in helping our children learn to communicate. It was not “dog training” nor child

My overriding urgency was to help my children learn how to talk, so that they could enjoy as independent and fulfilled a life as possible. Anything that could help unlock their potential for self expression and self direction was what was important to me, not taking sides in any professional or political dispute over causes or treatments for autism.

—Catherine Maurice

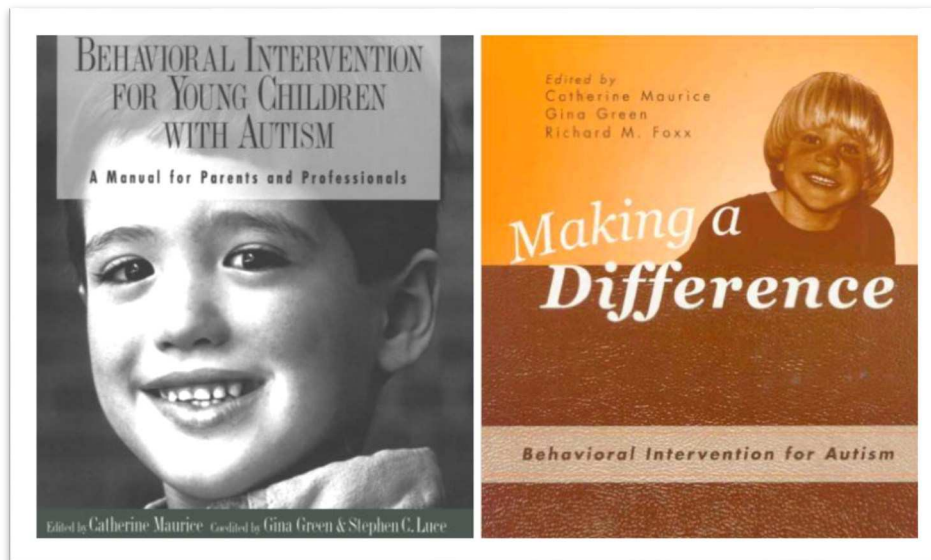
I wanted to talk about these difficulties and why they existed and maybe how we could do better in all these realms. I wanted to speak out about what I considered to be truth, as opposed to received opinions and clichéd thinking. As a mother, I knew I did not have any scientific expertise to offer, but I thought I could offer our lived experience as we made our way through these murky waters. Maybe that perspective could offer insights that could help others navigate their own journey with a child diagnosed with autism. I had no horse in the race regarding treatment, no vested interest in supporting ABA over any other treatment modality. My overriding urgency was to help my children learn how to talk, so that they could enjoy as independent and fulfilled a life as possible. Anything that could help unlock their

abuse. It was not a means of forcing our children into robotic compliance, but a way of helping them develop full capacity in language. Expressive, social creative language was the goal of our intervention, because language we believed then and now is the cornerstone of all learning and the means of structuring one’s own life, one’s own sense of self.

I wanted to write also as a witness to the early onset of autism, and how it begins to manifest itself in such subtle ways, so early. I knew that if I spoke about this, from the perspective of a layperson, recounting the minutiae of daily life with babies and toddlers, it could resonate with other

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parents more than academic studies published in obscure journals: Even though academic studies can contain truth, personal narratives written in a mainstream medium can reach far more people and can come across more vividly than such studies can. (Sometimes this is a good thing; sometimes it is not.) I hoped that by recounting the long drawn out process of fear, uncertainty, visits to specialists, and finally, multiple diagnoses all converging around the words “autism” and “PDD” (pervasive developmental disorder) I could possibly help other parents discover the truth of their own situations more quickly. Months can go by with people assuring you that *all is fine, she’ll talk when she’s ready, he’s OK, don’t be such a worrywart, Einstein didn’t talk until he was four years old, etc.* I wanted to affirm for parents that if they have concerns, it’s OK to keep asking questions and seeking reliable sources of information about early childhood development. As we know now, early intervention can be key to helping a child maximize his or her potential for learning and independence.

I wanted to talk about some theories of causation that I found particularly offensive. At the time our

children were diagnosed, there was no longer any direct talk about “refrigerator mothers” causing autism, but there was, and there remains to this day, vestiges of this thinking: What thinking? *Your child was somehow emotionally wounded as a baby, and withdrew into autism. Through proper love and emotional healing he will emerge, only when he feels safe and cherished and accepted for himself.* This has been called the Villain Victim Victor triad¹: The villain parent communicated “non acceptance” to the child (the victim) and only through the intervention of a savior therapist (the victor) who understands the child’s true needs will he emerge and trust again. This type of thinking still today undergirds some popular approaches to autism and will not go away, I fear, until science continues its march toward true understanding of the genesis of autism. When my daughter was in middle school, I discovered that *Dibs in Search of Self* was on her required reading list: This in my opinion is a true classic of the Villain Victim Victor genre: the mother is pilloried from beginning to end as a cold rejecting person who created catastrophic withdrawal in her child. The therapist, Axline, spends many pages painting herself as the

¹ A term coined first I believe by Lorna Wing.

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one who really truly cares for this poor little boy, truly understands him. (What narcissism reigns in some of these self anointed healers!) Books such as these cannot hurt my family or me any longer, but I worry about other families. Why? Because the mentality underlying the Dibs book is not the sole example of this kind of approach. I can think of at least a couple of other popular approaches still going strong today that propagate this notion that only “true acceptance” of the child will allow him to emerge and start chatting away once he feels safe and loved. For a fee, of course, they can teach you too how to love your child. So, I would say outrage was one of the catalysts when I sat down to write that first book.

David Celiberti: Outrage over theories of causation, and other problems as well?

Catherine Maurice: Theories of causation yes, but also all the craziness peddled as treatment. I wanted to talk, in *Let Me Hear Your Voice* and then later in the two manuals, about the scores (now hundreds) of treatments offered by the media, by parents, by people with made up degrees in made up fields, by people operating outside their area of expertise, by celebrities with conspiracy theories about Big Pharma, Big Government, by self important saviors, rogue doctors, unscrupulous profit mongers. When we published the two manuals (“we” being the professionals and parents who worked with me), we offered some chapters on the state of the evidence regarding many of these treatments. Those chapters were written by respected researchers highly trained to evaluate the quality of experimental design and to assess the evidence behind claims of treatment effectiveness. We had two goals: elucidate for parents and service providers the hard evidence to date for treatment x, y and z, and offer general guidelines for parents themselves to evaluate the quality of the evidence behind any treatment claim. We were not interested in telling people what to do; we did want to offer some tools to allow people to

make their own, informed decisions. Unfortunately, the “quality of the evidence” was conspicuously lacking for the vast majority of these treatment claims. When the books were published, I received angry letters, sometimes accompanied by threats of retaliation by “many many people.” The authors of these letters were offended that we dared say anything implying a lack of empirical support for chelation therapy, megavitamins, weighted vests, holding therapy, facilitated communication, auditory integration training, etc. etc. Autism intervention has for decades been characterized by this endless parade of dubious treatment fads, and I don’t think this will end soon.

David Celiberti: So these were some pretty serious critiques of the type of advice that parents were offered and are still being offered when they receive a diagnosis of autism. Did you see your books as fulfilling some other function?

Catherine Maurice: In *Let Me Hear Your Voice* especially, I wanted to talk about the reality of hope: Hope for a child with this diagnosis to eventually achieve self-sufficiency, self-expression. This can happen and has happened. There is no bio-medical cure for autism and maybe there never will be. But recovery - meaning the attainment of full communicative, cognitive and social functioning - is no longer outside the realm of possibility for a child diagnosed with autism. At the same time, I wanted to acknowledge there is a continuum of progress - not all children were going to achieve this level of independence, at least not under our present state of knowledge. ABA may be the most effective intervention we have now, but ABA does not pretend any knowledge about the underlying causes of autism and it does not promise recovery for every child. It offers the tools and methods to help every child learn. Some children will respond maximally to ABA and some will make much slower progress.

To elucidate the reality of differing responses, I invited other parents to contribute their own sto-

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Bogus treatments are not harmless. They bleed time from children and money from families and in some cases result in outright harm.

—Catherine Maurice

ries. In *Let Me Hear Your Voice*, in *Behavioral Intervention for Young Children with Autism*, and in *Making a Difference*, I invited testimonials from parents who I believe were every bit as involved as my husband and I were, every bit as committed, who even in some cases employed the same therapists we did, and yet, their children did not make the same degree of progress with the same rapidity as ours. The bottom line is that we can only have a certain amount of control over the quality of the intervention; we cannot predict how each child will respond.

David Celiberti: So you understand why parents would be open to anything that might give them hope?

Catherine Maurice: Of course I understand that. It's human nature. If a given treatment is only going to go so far and your child's future is at stake, most parents will be open to trying other avenues. But it's also a reality that hope can be exploited. The fact that ABA is not a cure all is no reason to simply shrug and yawn at the fakery peddled to desperate people. Bogus treatments are not harmless. They bleed time from children and money from families and in some cases result in outright harm. Witness the number of false accusations levied against parents throughout the "facilitated communication" craze, the harm that is still resulting today from the frenzied anti-vaccine movement, the rampant experimentation on children used as guinea pigs for every new "breakthrough" peddled on the internet. Every dollar, private or public, that is spent on pursuing and promoting quackery is money diverted from the

pursuit of real answers, real hope. Although it is fashionable to say "I believe in an eclectic approach" the fact is that "belief" is not a substitute for objective assessment, and the fact is that each component of that eclectic approach should be subject to the same scrutiny for effectiveness and safety as anything else to which our children are subjected. We need to balance open mindedness with critical thinking and a healthy dose of skepticism when it comes to the latest cures for autism. And the media needs to do a better job of exercising a similar level of caution, rather than stoking these frenzies, propagating pseudoscience and accepting uncritically every new miracle story in autism treatment.

David Celiberti: Overall, do you think you were successful in mitigating some of these problems?

Catherine Maurice: How effective was my work in elucidating these issues, or creating change where needed? I don't know. Who can judge that? I try not to think too much about my personal impact, because that way you can get caught up in the ego wars that rage in the autism world, and I think we all have to focus on something other than ego if we are going to make any progress together. I felt my job was to testify, and hope for the best. In some sense, I think things are better, whether because of my work or the work of others it does not matter. On the plus side, diagnosis seems a bit easier today; ABA is no longer excoriated quite as widely as in the past; more children are receiving the help they need early on. On the other hand quality programs are still hard to get into, insurance often doesn't cover all the costs; adults with autism are often left with few resources when they turn 21, we still don't understand what autism is and how we can best help the children and adults most affected, and the "crazy therapies" continue, on and on and on. There is still so much work still to be done, for generations to come, no doubt.

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David Celiberti: What are your hopes for the future of autism intervention?

Catherine Maurice: Well, I hope to see an increased awareness on the part of the public of what “evidence-based” really means, and I hope to see publicly funded treatment programs tied to that evidence. And, precisely because ABA is not a panacea, I hope that research continues into any other avenue that seems promising. I am glad that organizations such as Autism Speaks have the means to raise significant funds so that high quality research can continue into the possible causes and potential treatments for those affected. It will take a lot of hard work, but I have faith that the scientific process will yield more understanding of and more help for people with autism and their families. One day we will have a wider variety of treatments that are better able to help even those most severely affected.

David Celiberti: Some people today are opposed to the words “treatment” and especially “cure” when talking about autism. What are your thoughts on the “neurodiversity” movement?

Catherine Maurice: Oh Lord, David. Just when I thought I could retire into the sunset and peacefully learn how to knit or something, here you are asking me questions that inspire white-hot rhetoric across the blogosphere. Thank you my friend!

There seems to be a new book on neurodiversity every week now. I’ve been wondering about these terms: What does “neurodiversity” mean? That your brain is different from mine? Of course it is. We are all neurologically diverse. Every person is unique. Humans display a huge variety of personality types, ways of acting, ways of being, ways of

To call autism a manifestation simply of “neurodiversity” does not capture the reality of what autism can do to a child and to his or her life prospects.

—Catherine Maurice

thinking. To call autism a manifestation simply of “neurodiversity” does not capture the reality of what autism can do to a child and to his life prospects.

Maybe it’s time as well to question the definition of the word “autism” with respect to this movement. The criteria for an autism diagnosis seem to have expanded over the course of the last two decades, so that now, there are college graduates, holding high-level jobs, some of them married, who say they are “on the spectrum.” Perhaps we are moving toward a future where the word “autism” is becoming too broad to be meaningful. Steven Hyman, former head of the National Institute of Mental Health (NIMH) has offered the view that autism “*may turn out to be a family of brain-related problems that won’t respond to the same treatments.*”²

In any case, however it is defined, some within neurodiversity circles take exception even to the word “problem” let alone “disorder,” or any other such negative term. It’s not a problem, goes one argument: it’s another way of being, and those searching for a treatment or cure are rejecting children for who they are, and trying to force them into some draconian norm, where the majority wish to suppress, discriminate against – even “harm” – those they deem different. They write lengthy tomes on the Internet expressing outrage over this oppression.

One essay considered seminal in this movement scolds parents for even daring to grieve over this

² Quoted in “*The Autism Rights Movement.*” Andrew Solomon. May 25, 2008. New York Magazine.

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diagnosis, mocking them for having to give up their “*fantasized normal child*.” Rather than thinking “*I wish my child did not exist*,” lectures this author, what you [parents] should learn to do is “*speak our language*,” accept us for who we are. Mind you, this tract is written in English, so it is not clear what this other language may be. What is clear is that this person has mastered a means of communication that certainly allows him this soapbox. If only all kids with autism could have the same opportunity. And what is “our” language anyway? Who is this “our” and this “we” the author insists on using every other sentence? It’s a bit arrogant that anyone would presume to speak for all people with autism, and presume to lecture parents on how they should or should not respond to a diagnosis that has been known to wreak havoc on a child’s development.

I can’t speak for all parents, of course, but in my 25 plus years in this field, I have noticed that parents who seek treatment do so for many reasons, including self injurious or aggressive behaviors, but primary among those reasons is this: they want their child to have communicative language, the bedrock of human learning; Language, which gives a child the ability to speak her own thoughts, lead her own life, become who she wants to be; Language, which eventually frees a child to be his own boss.

David Celiberti: Why would anyone be against that?

Catherine Maurice: Well, clearly the neurodiversity folks already have language, so this doesn’t appear to be their concern. Their focus does not seem to be on the reality of how autism actually impacts so many children and adults, but instead on a conviction that they are being discriminated against – because they are autistic. The mantra that repeatedly appears is that the language of “disorder” or “disability” is insulting to people who are fine with who they are: it is wrong to

even speak in those terms, let alone lobby for a cure for a condition that some have even taken to calling a “gift.” Another oft-repeated argument is that people like Einstein or Beethoven or Steve Jobs were probably “on the spectrum” and it would have been morally wrong to try to make those geniuses fit into some kind of norm. And they too are on the spectrum and they are not going to be forced to change.

I find this argument puzzling: Who is trying to change them?

Moreover, these Einstein/Beethoven analogies ring false. It’s getting to the point where anyone can claim – retroactively – that any genius, any inventor, any artist was “probably on the spectrum” – and the implication is that people who are focused on curing or treating autism would have wanted to persecute these exceptional people. This argument is specious. No parent I have ever met is wrapped up in any thought of changing his or her genius child to render him less unique or because they want to squash her brilliant difference. Parents who hear this diagnosis are aware of the prognosis for autism as it used to be understood (not “Asperger’s” not “genius” not “artist”) and are aware of what autism can do to a child. They are usually consumed with more urgent priorities like:

- *Will I ever be able to have a conversation with my son, my daughter?*
- *How will he fare in school?*
- *Will he ever be able to hold down a job? Live independently?*
- *Will she ever have a friend?*
- *Will he have a happy life?*
- *What will happen to him after I die? Who will take care of her?*

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It is understandable in a way I suppose that some of the neurodiversity arguments denigrate treatment. Those who are most outspoken in their opposition to treatment or cure clearly don't need it – at least not for autism. Other people do.

—Catherine Maurice

For these parents, treatment does not mean “getting rid of the child I have” or ceasing to love that child. It means finding a way to give that child the tools and skills to free him, as much as possible to live his own life and make his own choices.

It is understandable in a way I suppose that some of the neurodiversity arguments denigrate treatment. Those who are most outspoken in their opposition to treatment or cure clearly don't need it – at least not for autism. Other people do. It seems to me that this focus on victimization certainly brings a lot of media attention, but at what cost to other young lives – young lives with huge, serious challenges?

What concerns me in this movement is not that anyone would want to advocate for more acceptance, love, concern and care for all people with autism, wherever they are on the spectrum. What concern me are three things:

- The threat to children, wherever and however their access to effective treatment is undermined or attacked
- The resurgence of hostility against parents

- The attacks against professionals who have dedicated their lives to helping families.

But do all neurodiversity people rail against treatment? Some of them protest “we do not!” but if not, they need to speak up more, as they are being drowned out by more extreme views. The rhetoric used especially against anyone who chooses or recommends an ABA-based intervention for a child is increasing, and it's troubling. In addition to the old clichés about dog training and harming children, many of the neurodiversity advocates describe parents who choose ABA as doing so only because of their own selfish needs, not those of the child. I have read blogs implying that parents who choose such treatment do so only because they are embarrassed by their atypical child. These bad parents will do anything to satisfy their narcissistic need to have “a perfect child.” I have read that anyone who chooses ABA treatment is persecuting a cohort of the human race. I have seen tracts painting behavioral therapists as borderline criminals and parents as child abusers. Somebody is always deciding that parents are the enemy: first they were vilified for having “caused” autism. Now they're vilified for wanting to treat it.

David Celiberti: Can you offer specific examples of this kind of rhetoric?

Catherine Maurice: Yes, I suppose at some point I have to cite some actual people or it sounds like I'm making stuff up. Michelle Dawson self-describes as “an autistic adult” who was diagnosed in her thirties. According to her own public statements, she is someone who is “intelligent,” who “speaks and communicates clearly” and whose “employment record is exemplary.” Like others in this movement, she rejects the language of disability or disorder as descriptors of autism, asserting instead that any problems “autistics³” may encoun-

³ The term “autistics” is the term Ms Dawson uses in her own writings. Many in the neurodiversity movement reject the term “person with autism.”

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ter are due to society's lack of respect for autistics' unique abilities and society's lack of accommodation for their needs. She has published astonishing certitudes about how autistic brains function, even in one tract describing the capacities and abilities of "all autistics."⁴ She equates treatment to the persecution of other groups who were misunderstood, oppressed and harassed throughout history, and over the past decade she has spent thousands of words publicly and personally critiquing parents and professionals in what she calls the "autism-ABA industry:"

"...Autism-ABA adherents include therapists, educators and instructors, parents, grandparents, friends-of-the-family; funding bodies, autism societies, professional and pressure groups; professors, lawyers, judges and journalists; politicians, bureaucrats...All have failed to notice that they themselves are behaving unethically."⁵

Her assertions about the unethical behavior of all these people go on and on, page after page, naming organizations and individuals, building her theme of treatment as persecution, as dehumanization, as harm. "*Behaviorists have as their goal extinguishing autistic behaviors and therefore autistic people*"⁶ is a typical statement.

In 2004 Ms Dawson intervened in a Canadian Supreme Court case where parents were seeking government funding for treatment. Her affidavit before the court stated that people with autism are smart, communicative, capable people, just like her, not defective the way the doomsayers always portray. Treating them is tantamount to outmoded

and discredited attempts to "treat" sexual orientation.⁷ Parents who seek ABA-based treatment for their children are "*denying [their] humanity.*"⁸

Fifty years ago Bruno Bettelheim penned some comments about mothers and fathers of children with autism. Among his many pronouncements, taken as gospel at the time, was this: *The precipitating factor in infantile autism is the parent's wish that his child did not exist.* We seem to be entering a new phase of parent-bashing, decades after Bettelheim's brutal reign supposedly ended: an age where neurodiversity champions accuse parents of "*wanting to extinguish their autistic child,*" "*wishing their child did not exist,*" "*harming them,*" and "*denying their humanity.*"

Ultimately the court decided against the parents, whether influenced by Dawson's affidavit or not I cannot say.

Do any of the neurodiversity activists resemble, can they speak for the little boy I saw just today? He is about 6 years old, completely non-verbal, darting constantly hither and yon, no interaction whatsoever with anyone, completely dependent on his parents, probably for the rest of his life unless someone, somehow, can get him some help. I watched as his parents followed him from room to room, never relaxing their vigilance, so patient and loving and just dealing with the reality of their child's severe challenges. Clearly, this little one is not going to function or learn in a typical kindergarten or first grade class anytime soon. Clearly, it's going to take some intensive intervention to help him learn some kind of communicative language. Who would dare attack his mother and father for doing whatever they can to lessen the effects of autism in their son?

⁴ Dawson, Michelle. 2004. *The Many Varieties of Being Written Off*. Retrieved from www.sentex.net/~nexus23/naa_wro.html

⁵ Dawson, Michelle. 2004. *The Misbehaviour of Behaviourists*. Retrieved from www.sentex.net/~nexus23/naa_aba.html

⁶ Ibid

⁷ An Autistic at the Supreme Court. http://www.sentex.net/~nexus23/naa_sup.html#1b

⁸ Ibid

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David Celiberti: So you fear that the neurodiversity movement is fostering a resurgence of anti-ABA sentiment?

Catherine Maurice: I believe that the neurodiversity premise holds the seeds of a potentially important perspective and I am waiting for a rational and cogent elucidation of that perspective. The idea that some people on the spectrum might not need treatment and might be offended at the notion of treatment or cure is not *per se* outrageous or illogical. But I am troubled that from the outset the manifestoes of this movement tend to minimize the devastating impact that autism has had on the majority of children diagnosed. And I'm troubled that so many of the arguments have been muddled by an anti-treatment, specifically anti-ABA animus, which is something that can harm other people's children and the parents and professionals who care for them. And I don't think this theme is confined to just a few extremist voices out there. The old shibboleths and stereotypes about ABA are resurfacing now in mainstream books and publications.

The new bestseller, *NeuroTribes*, by Steve Silberman, offers an interesting example to which I can speak directly, since it happens to concern the ABA-based approach with which I am most familiar, the one I describe in *Let Me Hear Your Voice*. I don't mean his book is focused on me – it's a wide-ranging discussion of the history of autism as seen through different perspectives. But he touches on my book and the approach we used when our daughter was diagnosed. As I read his comments, I was not particularly rattled by his mockery of my faith (*Catherine fell to her knees!*), or by his snarky description of my husband and me: "*They threw themselves into the role of being ABA co-therapists with the fervor of religious converts.*"

⁹ Silberman, Steve. 2015. *NeuroTribes: The Legacy of Autism and the Future of Neurodiversity*. Penguin Publishing Group.

I'm used to all that. To me it has become a hackneyed cliché to see parents who endorse ABA depicted as gullible, unquestioning cult followers. It would be futile as well to even comment on his insinuation that our daughter may have regained language through simple "maturation" or on his obvious scorn for the whole notion of recovery.

What is relevant to this discussion is the way he describes the complex and constantly evolving program that we organized for our children in simplistic, demeaning terms: Basically as a quest to train a child through punishment and food bribery. *Punishment?* We said "no" to certain behaviors. *Food bribery?* He reduces our program to a snapshot of Anne Marie sitting in a chair being coaxed to complete tasks through the use of m&m's, juice or food. Later, in discussing another family's approach in comparison to ours, he hones his point: "*Instead of aiming to extinguish Leo's autistic behaviors, as the Maurices' therapist had done, Fiona focused on teaching him skills that would enable him to care for himself and express his desires and preferences more effectively.*"⁹

This is just strange to me. I do not recognize our program or our therapists in this pastiche. In *Let Me Hear Your Voice*, I describe in lengthy detail not only the "teaching of skills" but also the step-by-step building of verbal communication, social rapport, and joyful interactions. There are multiple descriptions of praise, play, incidental teaching, and generalization across different settings – home, nursery school, the park, the grocery store, etc. Why ignore the many passages illustrating how parents, therapists and teachers worked to help both children regain full communicative language, to say nothing of self-care and "expressing preferences?" Does Mr. Silberman really believe that our children could progress through elementary school, middle school, high school, college and life without the ability to "express desires and

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preferences?” It seems that he really wants the reader to believe that our approach consisted of discrete trials in a chair, m&m’s, punishment and extinguishing autistic behavior. It makes me wonder if he actually read the book I wrote, or just picked through, looking for the bits and pieces that could reinforce a stereotypically negative view of ABA.

Why? Why present such a skewed view? I don’t know why anyone thinks the way they do or holds the opinions he or she holds, but as I read through *NeuroTribes* I was struck by two themes - themes that echo throughout the neurodiversity movement: the emphasis on autism as a “strange gift,” a different but wonderful kind of intelligence that has been misunderstood and unappreciated throughout history, and by the frequent descriptions of how children in decades past were abused in the name of treatment. As he delves into the history of autism, and the stories of the major players who shaped public perceptions and responses to autism, he discusses a parade of horrific interventions championed by this expert or that expert: electroshock therapy, hitting children, screaming at them, depriving them of food, trying to force “sissy boys” to change their sexual orientation, separating children from their “toxic” mothers, locking them in closets, confining them to locked beds, etc. In reading through all this, I thought “*Who would not find such behavior ethically and morally wrong, repugnant?*” No parent or professional that I have ever met endorses the primitive and cruel experiments from 50, 60, 70 years ago that are described here. With respect to ABA in particular, it bears repeating that this approach is not about any one man or one method and never has been. Over the course of the past fifty years ABA has become a field of experimental and applied research concerning human learning – a field to which hundreds of minds have contributed and a field that has steadily evolved in its understanding of how to maximize each child’s

individuality; it’s a way to help a child have more control over his own choices. I wish that parents scared off by terrible stories about ABA could witness the power of a son’s first words, a daughter’s joyful smiles under the care of patient loving therapists such as I have known over the years.

It was telling to me also that Silberman salutes and admires, in his final chapter, the important work being done by Michelle Dawson.

David Celiberti: Are you familiar other perspectives that should be considered by those seeking a different take on this matter?

Catherine Maurice: SIAT readers may wish to read the perspective of Jonathan Mitchell, a man diagnosed with autism as a child who struggles with complex challenges today and who offers his own remarks on the neurodiversity movement. No one person speaks for all people with autism, just as no parent speaks for all parents, but I think his voice should be heard. He asks: *Are the people who espouse this philosophy typical of autistic people in general? Do they represent the best interests of the majority of people diagnosed with this condition?* His answer is no and he explains why:

I am a diagnosed autistic, nonverbal, feces smearing at age 3, 8-year veteran of special education yet I do not share this view. I long for a cure for autism though a cure at age 52 is not the same as at age 3...

...My problems are many. I have been fired from multiple jobs and had to retire from paid work at 51 (I am 52 now). I have never had a girlfriend.../

I also have problems applying myself and staying on task which has made it difficult for me to do many things I wanted to do like learn computer programming... What do these things have to do with societal accommodations?.../

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*The internet has given a medium in which a small vocal minority can espouse their opinions and make it look like they are a much bigger group than they are. Most persons with an autism spectrum disorder have never had a web page or have expressed their opinions in the comments section of someone's blog and never will.*¹⁰

But tolerance and diversity of opinion don't work both ways I guess. When I researched Jonathan Mitchell I found that he has become a target of the neurodiversity community: *"The man is a threat... he is a hater....he hates himself"* rant the bloggers – and they do not spare his 86 year old mother: She is the one who turned him into *"a bitter hater."* Why? Because she tried to find treatment for him when he was young.

He still gets bullied, he says—but now it's by members of the neurodiversity movement. When not blaming his mother for his behavior, some have written mean-spirited songs about him. *"They've called me turdball and buttwipe. One girl said I was like a Jew that sympathized with Nazis and I would gladly jump into [a] crematorium."*¹¹

So a lonely man who wants to talk about his struggles honestly, along with his mother, has somehow become the target of Internet hate.

Who speaks for people with autism? Claims to speak for all members of any constituency - all women, men, gays, blacks, Hispanics, people with schizophrenia, people with autism - always seems to be the mark of a bullying movement that toler-

ates no disagreement. According to the Centers for Disease Control and Prevention, "nearly all children (94%) with ASD [Autism Spectrum Disorder] have special health care needs, defined as requiring health or related services beyond those required by children generally."¹² Maybe the neurodiversity people could recognize this fact and stop attacking families and professionals who are trying to provide those services, stop attacking people who find their own voice, as Jonathan has found his, and stop attacking parents of children with no voice, as a friend remarked to me recently. Her son is 25 years old and has no language, no voice save the advocacy of the people who love him most, his mother and father.

But the rhetoric against parents who choose treatment – especially ABA treatment - continues to grow and grow with every new bestseller on the Neurodiversity bandwagon. Some journalists - thank goodness - are taking notice, finally: *"Stop Whitewashing Autism"* is the title of an article in *Psychology Today*, in response to the Silberman book. *"NeuroTribes* calls autism a "gift" but parents paint a much different picture," writes Amy S. F. Lutz. To illustrate her point, she includes testimonials parents allowed her to share: Here's one of many:

You know I love my little girl more than anything but I hate autism so much I hate that nothing comes natural it all has to be taught I hate the meltdowns and lashing out I hate the self injury behaviors even more! I hate that even with meds we still have nights where we are up all night I hate the isolation and not having a normal life just simple things we can't do. I hate that she can't speak or even understand me! I hate that she won't eat and lives off pediasure!

¹⁰ Mitchell, Jonathan. 2007. Retrieved from www.jonathans-stories.com/journal/index.html

¹¹ Hayasaki, Erika. Feb 18, 2015. *The Debate Over an Autism Cure Turns Hostile*. Newsweek.

¹² Pringle, B.A et al: 2012. *Diagnostic History and treatment of school-aged children with autism spectrum disorder and special health care needs*. NCHS data brief, no 97.

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[sic] What I really want for her more than anything is happiness to be able to take her place without all the screaming even if she is in a damn stroller happy flapping away I don't care as long as she is happy!¹³

And how do the *NeuroTribes* fans react to this mother? Again, just one sample:

You don't deserve your child if that is what you think and this kind of talk honestly is hugely triggering. This is the kind of talk that paaaarents who commit filicide say to justify murdering their children! You should be ashamed of yourself!¹⁴

This person keeps posting and posting on her theme of evil parents, each time spelling it "paaaaarents," who knows why. To mock, I guess.

Does this movement have spokespeople who do not attack ABA professionals who are trying to help kids? Who do not accuse parents of wanting to "extinguish" their children who have this diagnosis? Who do not rip into parents or people with autism who want to talk about their struggles honestly? After some searching, I found someone who offers a more temperate view than the bulk of what I had to wade through to comment on this question: A supporter of the movement, Nick Dubin, PsyD, recognizes that autism can have "some disabling consequences" and counsels more understanding on all sides:

If high functioning autistics would take the time to truly empathize with the struggles faced by parents of severely challenged children on the spectrum, and be supportive of them finding treatments to alleviate

their children's physical and emotional suffering, the resentment felt by opponents of the neurodiversity movement might just begin to subside. And if the parents of more severely challenged children with autism could view autism as the diverse spectrum it is – a continuum with vast differences even on the higher-functioning, Asperger's end – one would hope the resentment Aspies feel would also subside.¹⁵

It's nice that he acknowledges the existence of severely challenged children, but I have a question: Which parents do not recognize that autism is a spectrum? Parents are told it is a spectrum from the first moment they enter the world of diagnosis, and are reminded in every single documentary or article on autism that it is a spectrum. It's called ASD, for heavens sake, which stands for Autism Spectrum Disorder. And yet, that does not explain why someone on the more verbal end of the spectrum would presume to lecture others on the "unethicality" of treatment, presume to intervene against parents in their quest for justice for their own children. And which parents are trying to cure or change or impose treatment on those legions of "higher functioning" people anyway?

David Celiberti: I appreciate how much time you have taken looking so carefully and compassionately on these myriad views. How do you synthesize all this?

Catherine Maurice: After reflecting long and hard on this question, and reading though so many impassioned opinions, here's my view, at least for now: I can understand why someone on the less severe end of the spectrum would have objections to the word "cure" and would want to lobby for acceptance and understanding of who he or she is, autism and all. Setting aside whether you think a

¹³Lutz, Amy S.F. Sept 28 2015. "Please Stop Whitewashing Autism." *Psychology Today*.

¹⁴Online commentary: Sept 28 2015. "Please Stop Whitewashing Autism." *Psychology Today* website.

¹⁵Dubin, Nick. 2011. "Neurodiversity. A Balanced Opinion." *Autism Asperger's Digest* online article.

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cure is a good thing or a bad thing, it is clear that people with autism have different perspectives on this question. Some like Jonathan feel that autism has robbed them of some of life's happiness. Others feel that autism is part of who they are and they don't want to be seen or treated as defective people. Others find support and comfort within a movement that brings them a sense of community and belonging. Others may have been diagnosed when little, received intensive intervention, and recovered to the point where they no longer meet any diagnostic criteria for autism— and they too are happy with who they are and with the opportunities opened up to them. It is important to listen to rational views on all sides of this issue. In my life, there is a person I love who probably meets the diagnostic criteria for Asperger's syndrome even though he has never received that label. I believe this highly intelligent young man with his very focused interests could benefit from a peer group who would open their arms to him in loving acceptance of who he is, whatever his quirks or differences. He has no friends and his mother has confided to me that he feels very lonely. Perhaps the neurodiversity movement could eventually help someone like him, if for no other reason than to let him know that he is not alone in the world. But this young man has language, he graduated from college, he has prospects for employment and independence. His needs are not the needs of all people with autism. Maybe, just maybe, a multiplicity of viewpoints can co-exist in harmony if all sides acknowledge the fact that some people need more intensive intervention and treatment than others, and parents who choose such intervention for their minor children have a right to do so, just as they have a right to educate their children and prepare them for life. Yes, we need to see every human being as unique, worthy of re-

spect and love, whatever the differences are. But the reality is that autism can create challenges, sometimes very severe, and no level of accommodations or goodwill is going to mitigate those challenges unless we find ways of helping those who need help. It's not just a matter being brilliant but geeky, or having a special but wonderful form of intelligence. Autism is something that can harm a person's ability to function and find connection in the world. And that's not because the world hates people with autism, refuses to accommodate their differences or wants to get rid of them.

It's because to build a relationship, hold a job or live your own life independently you need a certain level of functional language, self-regulation, cognitive maturity and social skills. The neurodiversity movement can help build support for all people with autism - but not by attacking professionals who have spent their lives trying to help people achieve their fullest potential, and not by reviling parents who are exercising their right and responsibility to help their child achieve these milestones.

Maybe, just maybe, a multiplicity of viewpoints can co-exist in harmony if all sides acknowledge the fact that some people need more intensive intervention and treatment than others.

— Catherine Maurice

David Celiberti: Thank you kindly for your honest and heartfelt thoughts on these topics. From the outset, your written words have opened not only doors, but hearts and minds as well.

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Thank You!

CLINICAL CORNER

Preventing and Addressing Bullying of Students with Autism Spectrum Disorder

By Lori Ernsperger, PhD, BCBA-D

October is Bullying Prevention Month so this installment on bullying prevention is not only a helpful resource for parents and clinicians, but also a timely one. It is unfortunate that bullying and other forms of harassment are a reality for so many individuals with autism and other developmental disabilities. In this edition of Clinical Corner, Dr. Lori Ernsperger offers readers some tools to help recognize and respond to such situations when they occur as well as resources for parents to advocate for effective bullying prevention policies in schools.

**Nicole Pearson, PsyD, BCBA-D
Clinical Corner Coordinator**

***W**e have a nine-year old daughter with ASD who started 3rd grade in a new school. She is coming home every day very upset due to other students calling her names and isolating her from social activities. We wanted her to attend the neighborhood school but how can we protect her from bullying?*

Answered by Lori Ernsperger, Ph.D., BCBA-D Executive Director of Behavioral Training Resource Center, LLC and author of Recognize, Respond, Report: Preventing and Addressing Bullying of Students With Special Needs

Unfortunately, bullying and disability-based harassment is a common issue for individuals with Autism Spectrum Disorders (ASD). As parents, you have a right to ensure that the school provides a multi-tiered framework of protection for your daughter to receive a free appropriate public education (FAPE) in the least restrictive environment and free from disability-based harassment. Start by educating yourself on the current legal regulations and best practices for preventing bullying in schools.

Recognize

Recognizing the startling prevalence rates of bullying for students with ASD is the first step in developing a comprehensive bullying and disability-based harassment program for your daughter. According to the Interactive Autism Network (IAN, 2012), 63% of students with ASD were bullied in schools. An additional report from the Massachusetts Advocates for Children (Ability Path, 2011) surveyed 400 parents of children with ASD and found that nearly 88% reported their child had been

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bullied in school. According to Dr. Kowalski, a professor at Clemson University, “because of difficulty with social interactions and the inability to read social cues, children with ASD have higher rates of peer rejection and higher frequencies of verbal and physical attacks” (Ability Path, 2011).

In addition to recognizing the prevalence of bullying of students with ASD in schools, parents must also recognize the complexities and various forms of bullying. Bullying of students with ASD not only includes direct contact or physical assault but as with your daughter’s experience, it can take milder, more indirect forms such as repeated mild teasing, subtle insults, social exclusion, and the spreading of rumors about other students. All adults must recognize that laughter at another person’s expense is a form of bullying and should be immediately addressed.

Finally, recognizing the legal safeguards that protect your daughter is critical in preventing bullying. Bullying and/or disability-based harassment may result in the violation of federal laws including:

1. Section 504 of the Rehabilitation Act of 1973 (PL 93-112)
2. Title II of the Americans with Disabilities Act of 2008 (PL 110-325)
3. The Individuals with Disabilities Education Improvement Act (IDEA) of 2004 (PL 108-446)

The Office of Civil Rights (OCR), along with the Office of Special Education and Rehabilitative Services (OSERS), have written guidance letters to all schools to clarify that educational institutions are held legally accountable to provide an educational environment that ensures equal educational opportunities for all students, free of a hostile environment. Any parent can access and print these *Dear Colleague* Letters and distribute them to school personnel working with their child.

- US Department of Education/Office of Civil Rights (October 2014)
- US Department of Education/Office of Special Education and Rehabilitative Services (August 2013)
- US Department of Education/Office of Civil Rights (October 2010)
- US Department of Education (July 2000)

Respond

Effective programs for preventing bullying of children with ASD in your daughter’s school should include multi-tiered interventions, starting with prevention strategies at the district level and extending down to individual level supports in the classroom. As a parent you should insist on a comprehensive and nuanced intervention that is not piecemeal or otherwise unidimensional. A multi-tiered framework for preventing bullying and disability-based harassment includes:

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1. District-wide and school-wide written policies and practices that focus on universal prevention strategies that target the majority of students, including students with ASD.
2. Classroom interventions that explicitly teach a “bystander education program” through integrated activities within the daily curriculum. A bystander education program teaches all students to identify when students may need help from peers, how they can safely intervene, and specific reporting procedures.
3. Individual-level interventions that focus on providing evidence-based supports and services to students with ASD who may be the victim or perpetrator of bullying behaviors.

As parents, you can request written policies and procedures from your district leaders and discuss classroom interventions with your daughter’s principal and teacher. In addition, because students with ASD are often victims of bullying, your daughter’s individualized education program (IEP) should include written goals for social skills, speech and language skills, and self-advocacy skills. Students with ASD require an educational approach that is concrete and sends a positive message on how to address bullies. Dr. Michelle Borba (2001) has designed *CALM*, a bullying prevention approach that can easily be taught to students with ASD, with simple rules and easy to follow steps.

- The first step in the CALM approach is to “Cool down.” Teach your daughter to recognize stress signals (e.g. sweaty hands, rapid heartbeat, and stomachache) and learn calming strategies such as deep breathing and positive value statements which can be practiced at home and at school.
- The second step is to “Assert Yourself.” Part of a social skills curriculum for children with ASD should include teaching assertive body language. Role playing and video modeling can assist in teaching non-verbal body language that can deflect bullying attempts.
- The third step is to “Look them in the eye.” Although eye contact can be difficult for some students with ASD, parents and school professionals should teach children how to face a bully and look them in the eye. Using visual supports may be beneficial in teaching eye contact during a bullying attempt.
- The last step in the CALM approach is “Mean it.” The speech and language therapist or other highly trained school personnel should work directly with your daughter on specific language scripts on how to respond to a bully. Students should learn a non-confrontational script such as “stop that,” “leave me alone,” “you are being a bully,” or “get away from me.”

Each step of the CALM approach can be taught discretely or through social narratives and other educational methods. Integrating the steps for the CALM approach within your daughter’s IEP will ensure that school personnel will monitor progress for mastering these skills. In addition, role-playing an incident of bullying at home can provide the necessary practice for your daughter to feel competent during an actual incident of bullying.

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Report

The bullying your daughter is experiencing may be disability-based harassment if it meets the 4-Prong criteria detailed by the Office of Civil Rights (see below). It is important to remember that even if the bullying of your daughter does not meet the 4-Prong criteria, a bullying incident may be considered a violation of FAPE and the IEP team should meet to consider any changes to her program.

In order to investigate and determine a violation, parents must report bullying to school officials. Unfortunately, not all states require reporting and some have insufficient reporting procedures. For more information on how to report bullying and sample letters for writing to the school principal, the National Bullying Prevention Center has numerous resources available for parents to utilize (please visit: <http://www.pacer.org/bullying/resources/parents/>).

The U.S. Department of Education and OCR have made it clear to school districts that they must implement a comprehensive approach to report an incident of suspected disability-based harassment, eliminate the hostile environment - which may include disciplining the bullies-, and monitor that the harassment does not resume.

Individuals with ASD, like your daughter, have a right to attend school, free of harassment, where school professionals teach acceptance and create a positive school environment that is inclusive of all students. In order to protect your daughter from the long-term ill effects of bullying, you must communicate your concerns directly with school personnel and maintain documentation. Request an IEP meeting to incorporate your observations into the IEP. Share the “Dear Colleague Letters” with school personnel and convey your intentions to closely monitor the situation.

Parents play an important role in demanding that school district leaders adopt policies and procedures for reporting and tracking bullying and disability-based harassment. For more information, please visit www.stopbullying.gov.

Bullying 4-Prong Criteria for Disability-Based Harassment

1. Student is an individual with a disability and receives unwelcome conduct or harassment based on the student’s disability,
2. The bullying is sufficiently severe, persistent or pervasive to create a hostile environment,
3. School officials know or reasonably should have known about the harassment, and,
4. School failed to respond appropriately to end the harassment. School personnel must take immediate action to eliminate the hostile environment and prevent it from recurring and, as appropriate, remedy its effects.

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*Parts of this response appeared previously in the August 2015 issue of OARacle published by the Organization for Autism Research., available at www.researchautism.org/resources/newsletters/2015/September2015.asp#Message

CONSUMER CORNER

Annotated Resources: Bullying

By Sunbul Rai, MSc, BCBA; Renee Wozniak, PhD, BCBA-D; Rachel L. Liebert

Highlighting the very serious issue of bullying, for this issue's Consumer Corner, our ASAT research team has created a valuable list of resources to help the parent whose child with autism is being targeted as well as teachers and school administrators who want to take action against bullying. To save valuable time, resources have been summarized succinctly to enable parents and professionals to quickly find a practical strategy to protect their loved one. Keep in mind that this worthwhile resource will also be archived on the ASAT website for future reference.

**Sabrina Freeman, PhD
Consumer Corner Coordinator**

1. National Autism Association (2015). *A & S bullying: 5 things parents can do* - www.autismsafety.org/bullying-tips.php

The National Autism Association (NAA, 2015) provides a brief and practical list of five steps parents can take to address and prevent bullying in school, including 1) preparing the team, 2) addressing bullying with specific goals in the Individualized Education Plan (IEP), 3) preparing your child, 4) monitoring your child for signs of being bullied and 5) using the complaint process. To prepare the team, NAA suggests politely making it clear that you will be involved in helping the team to avoid your child's victimization, and clearly communicating with teachers, administrators, the school board, and possibly the child's peers to provide information on the child's specific strengths and challenges, Autism Spectrum Disorder, and the problem of bullying. In the IEP, NAA suggests addressing bullying by including social skills and self-advocacy goals, applicable accommodations, a familiarization plan, and specific peer support. To prepare your child, it is suggested to talk to him/her about appropriate friendships and about bullying, obtain social skills training if possible, and to help him/her get organized and oriented to the school in advance. Next, NAA suggests monitoring your child consistently for signs of being bullied by visiting the school often and keeping the lines of communication open with your child and teachers. If the complaint process is necessary, be persistent while avoiding being overly emotional; begin with informal written resolutions, moving to filing a complaint if necessary, while keeping in mind your rights under "The Individualized with Disabilities Education Act" (IDEA, 2004).

"A & S Bullying: 5 Things Parents Can Do" is a quick read that may help parents take some simple first steps in addressing and preventing bullying issues for their child.

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2. Autism Speaks (2015). *Combating bullying* - www.autismspeaks.org/family-services/bullying

"Combating Bullying" is a compilation of information surrounding bullying of individuals with ASD, including links to a variety of Internet and other resources. Some of the links include the Interactive Autism Network (IAN)'s study on bullying experiences of children on the autism spectrum, a Special Needs Anti-Bullying Toolkit, the trailer for and information on *Bully: A Documentary*, links to almost 20 books, 10 websites, and to other resources including a DVD and a list of signs that your child might be being bullied. The compilation addresses bullying of individuals with ASD and Asperger's Syndrome, and includes information on bullying in schools, cyber bullying, and

more. Information may be useful for parents, caregivers, educators, school administrators, individuals with ASD, and peers/friends of individuals with ASD.

3. Autism Intervention Research Network on Behavioral Health (2013) - *Remaking recess* www.airbnetwork.org/remaking.asp

The Autism Intervention Research Network on Behavioral Health provides access to a booklet on a social skills intervention called "Remaking Recess" for use in the school setting. The booklet provides a treatment overview (helping children with ASD learn to engage with peers in the school-setting) and a brief summary of playground engagement states (solitary, onlooker, parallel, parallel-aware, joint engagement, games with rules) followed by specific strategies that can be implemented at recess time. Intervention strategies are included for a variety of situations, including 1) transitioning to an engaging activity and setting up, 2) providing popular developmentally-appropriate games and activities, 3) in-vivo social skills instruction, 4) facilitating peer conversations, 5) playing games, 6) sustaining engagement, 6) fading out of an activity and 7) a quick guide to boosting peer engagement. One of the main purposes of the intervention is to prevent bullying by aiming to improve the social inclusion of elementary-aged children with ASD by means of facilitated interactions with peers. *Remaking Recess* may be useful for individuals in educational settings who wish to take proactive steps to reduce bullying.

4. Committee for Children (2015). *Second step bullying prevention unit* - www.cfchildren.org/second-step/research

The Committee for Children is a non-profit organization that uses education with the aim to prevent bullying, child abuse and youth violence. The Second Step Bullying Prevention Unit is a current initiative through The Committee for Children and is aimed at the reducing bullying and peer victimiza-

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tion. The website includes information on the Second Step Bullying Prevention Unit Program as well as that program's outcomes. It comprises an article on the role of social-emotional learning (SEL) in bullying prevention efforts and highlights the importance of specific social and emotional skills taught in SEL programs, which include 1) empathy, 2) emotion management, 3) social problem solving, and 4) social competence. They indicate that the implementation of the Second Step Bullying Prevention Unit can help empower schools to prevent and reduce bullying. It may be useful for professionals and parents alike to help them better understand specific skills that need to be taught to children to help prevent bullying.

5. AbilityPath.org: Support for Parents of Children with Special Needs (2014). *Bullying - www.abilitypath.org/areas-of-development/learning--schools/bullying/*

AbilityPath.Org provides many resources on their website around bullying but one of the highlights is their comprehensive report on bullying that is aimed as a support for parents of children with special needs. The report is entitled "Walk a Mile in Their Shoes: Bullying and the Child with Special Needs" and emphasizes the "silent epidemic" of bullying that children with special needs face on a daily basis. It has several sections, which include: an overview of the report, testimonials from parents and children, targets: children with special needs, statistics, signs of being bullied, cyber bullying, teachable moments, the IEP, the law, the experts, the anti-bully program, and the call to action. Furthermore, it also has several parent toolkits along with a teacher toolkit to help caregivers identify signs of bullying, and it highlights proactive steps that can be taken to protect a child with special needs. The information is also geared towards cyber bullying, which is bullying that can be conducted through the use of technology. For example, one of the parent toolkits stresses the importance of protecting a child with special needs by teaching the child not to reveal personal information online, limiting online time, reviewing security settings on the computer and so forth. "Walk a Mile in Their Shoes: Bullying and the Child with Special Needs" promotes awareness, provides resources on bullying and its impact, and may be useful for parents, caregivers, teachers, administrators and other professionals working with children with special needs.

6. PBIS: Positive Behavioral Interventions & Supports (2015). *Bully prevention in SWPBS - www.pbis.org/school/bully-prevention*

PBIS: Positive Behavioral Interventions & Supports (2015) provides bully prevention manuals for the elementary, middle, and high school levels. The manuals are meant as a resource for the school setting and aim to provide students with the tools needed to be free of bullying through the use of school-wide positive behavior interventions and supports. The program described in the manual is divided into six lessons and focuses on the "stop/walk/talk procedure" for gossip, inappropriate remarks, and cyber bullying. The stop/walk/talk procedure involves physical and verbal components with examples provided of when they can be used appropriately and non-examples, of when they shouldn't be implemented. The manual emphasizes teaching the skill, followed by practice and role-playing for a variety of scenarios. The lessons are easy to read and are ready for implementation in

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the classroom setting. PBIS's bully prevention manuals may be useful for teachers or other educators in school (or similar) settings.

7. National School Climate Center. (2015). *Educating minds and hearts... because the three R's are not enough* - <http://schoolclimate.org/>

The National School Climate Center is an organization that utilizes relevant research to establish and distribute guidelines to encourage acceptance and safety in schools. The Center offers professional development programs for educators, parents, and after-school supervisors to better understand and promote children's social and emotional wellness and communication. Their website offers guidelines to help educators and parents establish and maintain safe and comfortable schools and homes by understanding social and emotional learning. The "Bully Prevention" section of the website includes a toolkit called "The Breaking the Bully-Victim-Bystander Cycle Tool Kit". This resource may be useful for educators who wish to create a positive school climate.

8. The Bully Project. (2015) - www.thebullyproject.com/

The Bully Project is a website that aims to take action on bullying. It focuses on a documentary about children who were bullied during the 2009-2010 academic year and how their parents supported them and modeled "upstander" rather than "bystander" behavior. The website invites users to share their own stories and host or organize screenings of the film to raise awareness. The site also includes tools (including DVDs and toolkits that can be purchased) for students, parents, advocates, and educators, with a section devoted to individuals with special needs. The tools for educators are also available in Spanish. The "Roadmap to Building a Caring and Respectful School Community" includes work that was produced with the assistance of the Making Caring Common Initiative at the Harvard Graduate School of Education. The website also provides interested individuals a platform in which they can take action by joining regional anti-bully project teams. This resource may be useful for those looking to increase awareness and to take steps on reducing bullying.

9. Pacer's National Bullying Prevention Center (2015). *The end of bullying begins with you* - www.pacer.org/bullying/

Pacer's National Bullying Prevention Center's website was developed for children and teenagers to be part of a social cause to end bullying. It includes a section dedicated to students with disabilities with legal information and template letters for parents to send to their child's school to serve as notification of a bullying situation and a written record of having done so. The website also directs children and teenagers to other helpful resources including KidsAgainstBullying.org and TeensAgainstBullying.org. Ample information is provided about National Bullying Prevention Month (October) including a brief history, opportunities to register for events, key points to make should you wish to give a presentation, and directions to request a governor's proclamation. Educator toolkits are available under the resources tab, and they include classroom toolkits, community toolkits, student-created toolkits, and activities for youth. Additionally, there is a guide for planning school events, and a peer advocacy guide. This website may be useful for children and teenagers who want to make a difference and provides tangible resources to reduce bullying.

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10. U.S. Department of Health & Human Services (2015). *Stopbullying.gov* - <http://stopbullying.gov>

This government website provides a wealth of resources across a variety of areas, in both English and Spanish. An array of topics is covered with related subtopics and links. General topics and subtopics include: *what is bullying* - definition, roles kids play, and related topics (e.g., harassment, teen dating violence, peer conflict and more); *cyber bullying* - what is it?, how to prevent it, how to report it, and risk factors; *who is at risk* - warning signs, effects, and considerations for specific groups (including bullying and youth with disabilities and special health needs); *preventing bullying* - how to talk about it, prevention at school, working in the community, and a training center which includes videos, reading modules, research and statistics, training manuals, toolkits, user guides and additional resources; *responding to bullying* - stopping it on the spot, finding out what happened, supporting the kids involved, and being more than a bystander; and *get help now*, which includes steps to take to resolve a range of bullying situations. Additional sections include links to both federal and state policies and laws, a blog, and news releases (including media guidelines). Several resources may be useful for education/training including images and info graphics, over 30 videos, and hundreds of links to campaigns, tips, toolkits and trainings, research, evidence-based programs, podcasts, conference materials and webinars. When searching for a resource, specifics can be selected to narrow the search by topic, type, source type (federal or non-federal) and date. This website may be useful for parents, educators, the community, teens, kids, and anyone wanting to learn more about bullying and gain access to resources to fit almost any need.



The advertisement for Coyne Associates Education Corporation features a central logo of a tree with two children swinging on a swing set. Below the logo, the text reads "Coyne Associates Education Corporation". Underneath the logo, the tagline "A model of excellence in early intervention service delivery" is written in a green, italicized font. At the bottom of the advertisement, there are three photographs of children: a girl covering her eyes, a group of children sitting on a bench, and three children giving thumbs up. Below the photos, the website "www.coyneandassociates.com" and the Facebook page "www.facebook.com/coyneandassociates" are listed, with a Facebook 'f' icon next to the URL.

PERSPECTIVES

Interviews with Connor Archer from The Courageous Steps Projects and His Mother Jessica Archer

By Franca Pastro, BA, ASAT Board Member

In this issue of Perspectives, we are featuring Connor Archer and his organization, The Courageous Steps Projects, a fundraising organization that honors and supports people who have taken steps to overcome challenges. We have also conducted an interview with Connor's mother, Jessica Archer, who gave us better understanding and appreciation of Connor's remarkable journey and achievements.

Franca Pastro, BA
Perspectives Coordinator

Interview with Connor Archer

Franca: I visited your Courageous Steps Project (CSP) website, Connor, and I must say - you have created an impressive organization with such honourable causes! What motivated you to start CSP and what projects are you currently working on?

Connor: After my challenges of overcoming obstacles of autism, I saw a need in our society - helping other young children with challenges. It started with summers spent at The Green House Nursery School, where I was a student, helping with the garden and painting steps, and then eventually, two years ago, the Courageous Steps Project came to be. With Courageous Steps, I have a few projects: the Back to School Drive to provide school supplies to many area schools for students with and without disabilities, and the School Technology Drive to get computer devices for the students and staff. For students graduating from Old Town High School, I began the Scholarship Fund for students (with or without disabilities) who have overcome or are living with challenges to order to help them achieve their educational goals. My latest project is the "One Word" video which is a video you can watch on my website - I want to educate others about focusing on the person, and not on the disability.

Franca: Managing CSP requires a lot of work and commitment, especially when you are still a full-time student. How do you manage?!

Connor: My mom more than anyone helps me with Courageous Steps. She drives around and helps me get sponsors, and solicits donations in gift cards and items for silent auctions for my events, so that way I can be a full-time student and athlete, and achieve times in my running that are impres-



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sive. We brainstorm ideas for fundraisers together and think through the details together. She usually helps to write my speeches as we talk over what I want to say, and with organizing my day because she understands how my brain works - we are a good team. I also ask my friends to help me volunteer at my events, and help me get people to show up at my events. My dad helps me with my silent auctions, and contacts people with emails, which helps me get more proceeds quicker, and takes less energy from my end. As far as Courageous Steps is concerned, I created and manage the website all by myself. I enjoy technology and the upkeep of a website that represents Courageous Steps in a clean way.

Franca: What are your future plans?

Connor: My future plans are to go to a four-year college. I plan on attending Husson University or the University of Maine as they have good business management and technology programs. I know I have a strength in the technology field and I think I can be very good at business, as I have worked to build my Project and my plan is to continue and expand it. I also want to minor in coaching, as I want to be a distance track coach one day - I love running and want to share my passion.

Franca: I can imagine you've gone through tremendous changes in your life. What has helped you overcome the challenges associated with autism?

Connor: "It takes a community to raise a child." It takes therapists, parents, siblings, friends, teachers, psychologists, doctors, community members, etc. I was fortunate to have so many of those support systems in place, to help me overcome those challenges. My mom made me do some things that I didn't want to do through the years. She pushed me out of my comfort zone because she recognized that is what I needed to learn and be an active student and citizen. It was not always easy to do new things and sometimes I still resist, but she always encourages me and reminds me that, with time, new things won't be as hard. I get tired and sometimes I feel stress because I have a lot to do and a lot I want to do, but my family is very, very supportive and they help me whenever I need it. So many people had to be a critical part of my life, whether they knew it at the time or not, to get me to where I am today and I am so grateful. I want to give back and to show others that even the smallest action can make a difference.

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Franca: What would you say to other individuals with autism who are beginning to plan their future?

Connor: If you are an individual living with autism, perseverance and determination are the two words that come to mind. There have been very few days in which I have not had to persevere in some way and determination has helped me to get to where I am today. There are going to be tough days ahead. I think of the achievements that I have already made, and I continue to strive to reach goals, as many others should as well. It may take months, years, and decades, until you see the impact. But it is worth it when you do!

Interview with Jessica Archer

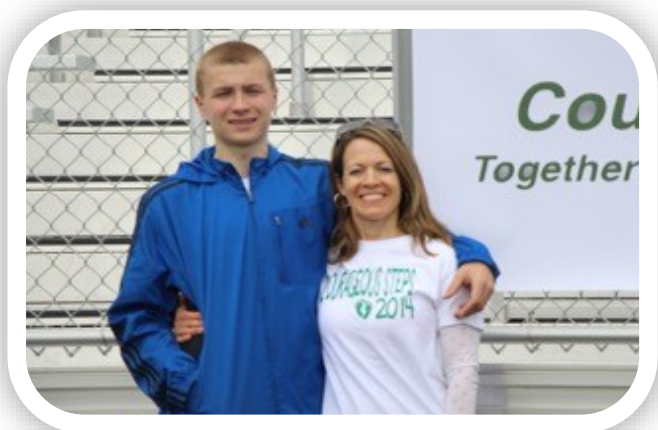
Franca: It is hard to really appreciate Connor's achievements without knowing where he began. Can you share your journey with Connor from the time of his diagnosis?

Jessica: Connor was diagnosed with autism shortly after his third birthday. We became concerned with his development when he was around 18 months, thinking that he might have a hearing problem because there were times that he would not respond to our voices. He was a very happy, content baby, but he did not seem interested in typical things and events. For example, during his second Christmas (22 months old), he was not really interested in the presents and tree like his older brother had been at that age. He was content to play with a toy that made musical sounds, pressing the same buttons over and over again.

Connor would interact with our family by smiling and laughing, but he did not talk to us. He would listen to stories; however, he would not interact with the story. He was pretty much oblivious to visitors and preferred to run into the other room and listen to music or press buttons on toys, but never really played with them in the traditional sense. We shared our concerns with our pediatrician, and we were told that some children just acquired language later. It was more than just language acquisition, though. The most impactful moment for me was leaving home to give birth to my third son and hearing about Connor's reaction from my mother, who was looking after him. He was very upset, tipping chairs and throwing things, crying, but unable to speak (because he could not form words). Later that day, my mother brought Connor to the hospital. I remember, so clearly, him looking at me, smiling, then lying down on the floor with his blanket and falling asleep. He was exhausted, but knew that his mommy was still part of his world. I knew at that moment, that I needed to find answers to help my little boy.

Franca: After diagnosis, what followed?

Jessica: Connor started interventions shortly after his diagnosis of autism. He began with



Connor and Jessica Archer

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speech therapy, but that was unsuccessful because he did not have receptive language skills to understand the commands of a speech therapist. We felt he needed behavioral interventions first. Because he could not communicate, he got frustrated and often knocked things over, emptied containers of toys and sometimes he was aggressive (hitting, biting). We visited a number of schools that would provide early intervention to teach him the skills that he needed, but it was not until we stumbled upon The Green House that I knew I had found the right school.

I was sold on the fact that it was an inclusive program and knew that, in order for Connor to learn typical behavior and language, he needed to be exposed to typical behavior and language. The Green House provided the best of both worlds: direct instruction (Applied Behavior Analysis intervention supervised by a qualified Board Certified Behavior Analyst) and kids learning while in the presence of their typically developing peers. He needed to be able to "practice" his skills in a real world setting with continued support from teachers who could take skills learned in a 1:1 setting and have him generalize them with peers.

Connor began his 40+ hours/week of intervention that fall (3.5 years old). We started teaching him sign language and used the PECS™ system for about a year as he SLOWLY acquired language. We had to teach him language by teaching sounds, then sections of words, then words, then phrases, then sentences. The process was arduous. His apraxia was very significant and the challenge to develop language was daunting for him and his teachers and therapists. Motor planning was a huge hurdle, not only with moving his mouth to create sounds (and eventually words), but moving his hands and body to do almost anything.



Connor during his graduation ceremony

Franca: How much involvement did you personally have in Connor's development?

I really knew very little about autism when Connor was diagnosed 14 years ago. I did know, however, that I would need to help him to learn; that was obvious. I started reading many books, taking classes at the University of Maine, eventually earning a Master's degree in special education and a Certificate of Advanced Study in special education and literacy. I also learned from sessions with Connor's therapists and teachers. They showed me how to continue the learning process that Connor received during his 1:1 sessions. I quickly learned that Connor would need many additional hours of reinforcement and teaching at home, too, in order to learn skills and make gains.

This continued right into his public school years. I recall sitting in his IEP meetings and explaining to teachers that there was simply no way that they (his teachers) could teach him all he needed to know during the six hours he attended each day in school. I requested materials and frequent communication

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with teachers in order to be his “at home teacher.” Connor worked hard, but he really did not know that his schooling, year round and extended days (4-6 more hours) was not the norm. He had started at such a young age and I think much of his current work ethic stemmed from that early schedule and the need to put in so many hours in order to learn so many skills.

Franca: As all this has unfolded over the years, how has it impacted your life personally and as a family?

Jessica: I am a better teacher, parent, and overall human being for having Connor in my life, and I believe the other members in our family would concur because Connor has taught all of us that life can have insurmountable obstacles and each day can seem more daunting than the previous, but it is necessary to just keep moving forward. Connor has taught all of us that we need not fear failure because it is a critical part of learning. He has taught us how to be genuinely happy and how powerful it can be to give back to those who have helped along the way.

Franca: Is Connor presently in any form of therapy or receiving services?

Jessica: Connor receives very few services now. He still has a case manager at school who helps him to organize his schedule, especially during more stressful times, such as the start of a new school year, mid-term and finals week, and other potentially disruptive events. Connor has learned, through years of role-play and modeling, how to be a tremendous self-advocate for what he needs to succeed. He also receives speech and language services twice a month to help with inference skills and building his vocabulary, and I continue to tutor him.

Franca: What is Connor’s take on autism?

Jessica: Connor is fully aware that many individuals with autism are impacted differently. It took an extraordinary amount of courage for Connor to share his story of an individual living with autism in a health class his sophomore year. When an assignment called for describing an individual with a disability, he selected autism and told his story. He was very nervous about sharing his story because he did not know how his peers would react: “Would they look at and treat me differently? Would they tease me?” To him, his worries were very real as he was a 16-year-old and when you are that age, your peers are very important.

He wrote a story about a little boy's journey with autism - including all of the obstacles. At the end of the story, he revealed that the story was about him. As he read the story, students who had known Connor since he was very young, knew the story was his own - they were the ones who cried. Others, sort of knew, based upon their observations of Connor over the years - they were the ones who smiled and nodded their heads thinking, “That makes sense.” The remainder had no idea and were very surprised. One thing was common of all the students’ reaction that day - they were proud of Connor and they expressed how incredibly brave and courageous he was to reveal his struggles and disability.

That day changed Connor. Word spread fast about what he had done and the next day he spoke to another health class full of more peers his age. It was as though a tremendous weight had been lifted off of his back. He no longer had to explain why he had to use a laptop to write because he did not have finger dexterity to write well. Everyone understood why it was often hard for him to even say,

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"Hello!" and keeping a conversation going was even harder. Not only did his peers accept him, they embraced Connor for the unique individual he had always been and would always be.

Connor has stated that he embraces autism and I believe what he means is that he embraces what it has brought into his world. He has faced challenges for years and he still does. He has needed tremendous amount of support and he still gets it. Connor recognizes that so many people who have been so important in his life are a part of his world because of his diagnosis. For that he is grateful and, proudly, through Courageous Steps, he sees himself as "giving back." Having autism has not been easy for him and it never will be, but Connor understands that he was meant to be on this journey that would not have happened had he not been diagnosed with autism. He embraces the life that it has given him and the path that lies ahead as an advocate for others who also face challenges.

Franca: Do you have any advice for other parents/caregivers of young adults with autism who are thinking about their future?

Jessica: My advice for other parents/caregivers is to take one day at a time. It is hard to raise a child with a disability. It is exhausting and very frustrating at times. There are times I have felt very alone. It has also brought tremendous joy to my world because of the victories that to others might seem very trivial, but to me are monumental. None of us know what the future will bring; all we can do is to plan the best we can, seek support from others, and every day find the sparkle that makes each of us unique.

Connor Archer was diagnosed with autism spectrum disorder at the age of 3 and this year he graduated from high school. He lives with his parents and brothers in Old Town, Maine, USA.

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- ★ All families will be empowered with skills in identifying and choosing the most effective, scientifically-validated interventions for their child.
- ★ The media will educate and not confuse parents by providing accurate information and asking the right questions.
- ★ All providers will be guided by science when selecting and implementing interventions and use data to demonstrate effectiveness.

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ASAT's Sponsors indicate 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 scientific 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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The tasks of educating the public about scientifically-validated intervention and countering pseudoscience are daunting ones, and ASAT appreciates the support of all of our sponsors.

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FROM THE ARCHIVES

What Caused That?

By John Jacobson, PhD, BCBA

In this edition of “From the Archives”, we highlight a piece by one of the founding fathers of ASAT, John Jacobson. Not only a founder of ASAT, but also a former president of the American Psychological Association's Division 33, Dr. Jacobson's insight and impact cannot be overstated. In this piece, he helps shed some light on how autism researchers identify the cause(s) of autism and ASD. Of equal importance, Dr. Jacobson also touches on the impact of correlations in science - and how these correlations do not necessarily give us the useful, accurate information that we think they do. Consumers and practitioners lost Dr. Jacobson on May 8th, 2004. His contributions to the field of behavior analysis and autism research live on to this day.

**Patrick O’Leary, MA, BCBA
Newsletter Content Coordinator**

Questions of cause are very difficult questions to address with full candor and confidence, not only in the case of autism spectrum disorders, but also in other conditions for which diagnosis is made based primarily on behavior. For example, some individuals speculate or assert that biological and/or toxic agents in the MMR vaccination cause autism. This article will focus upon that controversy to explore the complexities of cause and effect.

The scientific method is a process by which researchers seek to answer a variety of questions. Some of these questions do not involve causes, while others do. For example, neurological or neuroscientific studies may attempt to determine differences typically present in the structure or neurochemical features of the brains of children with ASD, compared to the brains of same-aged children without diagnosed disabilities. In other words, the question posed is not what causes autism, but rather what differences exist in autistic versus non-autistic brains.

On the other hand, some studies do attempt to identify causes such as causes of a disability. To do so, certain tasks must already have been accomplished. For example, the disability must be well-defined. The decision that the disability is present or that the disability is not present must be accurate. The group that is defined as having the disability must be as homogeneous as possible. That means, for example, researchers should consider the question of what causes autism separately from the question of what causes PDD or Asperger’s syndrome. This is not to suggest that autism, PDD and Asperger’s are not a spectrum as typically thought, but rather that the question “what causes autism?” is a much more specific question than “what causes autism spectrum disorders.” There is also the consideration that, because the diagnosis of autism and other ASDs is based on breadth and severity of effects, logically, differences in brain structure or other features should be more apparent for these children.

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Assuming that we can accurately decide whether children have autism, and we are able to identify biological differences between these children accurately as well, we could then approach the question of cause in two ways. Taking into account possible multiple medical or neurological factors, we can conduct a detailed investigation into the backgrounds and developmental history of the children, identifying events that differ between diagnosed and non-diagnosed children. In this approach, we start with a group of children who are identified, and then look back on their histories. This is termed a retrospective study. Retrospective studies are important to conduct, but there are also challenges associated with them, including documenting that reported events occurred, reliance upon incomplete or differing clinical records, and the fact that universal screening for disabilities like autism usually does not exist, so only the children who happened to be identified and referred are included in the study. Children who are referred are likely to differ in several ways from those who are not referred, and some of these ways may be related to risk factors for autism.

The preferred method for conducting a study of causes is to use a prospective approach. Prospectively, one begins by using outreach to screen a population of children for a disability, to detect instances of the disability that might not otherwise be identified, as well as those who would have been identified. Then, background and history data can be collected on a group that is more likely to actually represent children with autism or any other condition. Historical information could include vaccinations and other medical events (e.g., exposure to general anesthesia, recurrent health conditions), as well as information about child development. More ideally, a prospective study would follow children from birth, and all of the information needed to consider causes could be collected as events occur. This would assure that the information is more complete, and in a standardized form. In the case of autism, even though it is now being identified more frequently, this approach is very difficult to carry out; for each child who may develop autism, there may be from 250 to 1,000 other children who need to be screened and followed. For this reason, some researchers may attempt to use prospective approaches to study causes of autism within larger studies that look at child development in large population groups, and consider a variety of disabilities. This often means that information that is specific to risks for ASD may not be fully collected.

Of course, there are other research designs that can shed light on causes of disabilities. Certainly genetic studies can indicate genetic factors that increase risk for a childhood-onset disability. Research with animals that involves brain surgery during early development that result in behavioral changes akin to those typical of a disability may also be suggestive. Basic research at the level of neurons and the effects of toxic substances and side-effects of medications may also be suggestive. But... there is no substitute for actually studying the occurrence of a condition among children prospectively.

Why do we need scientific studies to indicate what the causes of a condition like autism might be? Why isn't it enough that some research might identify some differences between children with autism and their peers? First, some differences that are identified initially do not necessarily differentiate children with autism from those who are accurately diagnosed as not having autism. For example, research findings have suggested the unexpected presence of measles virus in the gastrointestinal tracks of children with autism, but subsequently at least one report has found this for children without autism as well. This does not mean, in and of itself, that the initial gastrointestinal findings are not possibly suggestive, but does point out the need for careful assessment of the likelihood that particular factors are

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plausible risk factors. In this case, scientific research needs to address why, if gastrointestinal measles is a risk factor or cause, or reflects a risk factor, some children are affected, and others are not.

But, if many people develop a consensus that a given event—vaccination, for example—is regularly observed to occur shortly prior to detection of autism, is this not sufficient to warrant research on this issue? The short answer is yes—whether observed by parents, clinicians, educators, or researchers, events that may be plausible causes or risk factors for a disability should reasonably be studied. Parents or others in the lives of children with disabilities may certainly detect events that are not apparent or considered by clinicians or researchers. But the fact that a belief is widely held is not, in itself, evidence that the belief is valid or accurate.

The brains of human beings are structured and function in ways that are the joint product of evolution and experience. One of the well-known biases associated with human perception and thinking is the tendency to conclude that there is a cause and effect relationship between two events, when it can be shown through precise research that this is not the case. Carl Sagan, in his 1997 book, *The Demon-Haunted World: Science as a Candle in the Dark*, referred to such tendencies as “irreducible human error.” To err in this manner is human, but to insist that reliance on mere consensus is sufficient to accurately identify causes of events, such as the occurrence of autism, is folly. Errors of this type may be even more likely when the identification of a chain of cause and effect is especially important to the person making a judgment about cause and effect; many parents of children with autism believe that identifying the causes of autism, for their child and other children, is important. This may increase the chances that some or many may conclude that certain, unproven events are causes of the disorder, without solid evidence. However, this is a very human thing to do, and clinicians and researchers are prone to do this as well.

The critical distinction that needs to be made is between correlation and causation. Correlation means that two events tend to occur together. When one does not occur, the other tends not to occur as well (called a positive correlation); or that when one occurs, the other tends not to occur (called a negative correlation). Sometimes correlations, like cause and effect, are perceived accurately, and sometimes they are not. But while necessary for showing cause and effect, correlation does not prove cause and effect. Sometimes correlation might be presumed, because of cultural factors; for example, autism is often diagnosed, by definition, at ages when children are subject to frequent vaccinations. Thus vaccinations and autism could be hypothetically correlated, despite the fact that there is no present scientific evidence that this is the case. Correlation does not in itself show causation, because the fact that two events occur together may be influenced, or caused, by a third factor that has been ignored, or that was not studied.

Causation, on the other hand, requires a higher standard of proof than the fact that two events occur together (that is, have a positive correlation). Proving causation, or that an event is a risk factor for a disability, requires that several conditions be met: (1) the purported cause has to consistently or always occur before the purported effect; (2) when the purported cause occurs, the effect regularly occurs; and (3) when the purported cause does not occur, the effect tends not to occur, is less likely to occur than it does generally, or does not occur at all. Other criteria associated with the strengths of prospective studies also need to be met; for example, that the group of people studied is representative of the larger group of people with the condition (in this case, all children with autism or all children with ASD).

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This can be done by including all children in a general population with the condition, or by randomly sampling the children with the condition. But, if sampling is used, there also must be a sufficient number of children to generalize to the larger group of children, and the required number to do so increases as the complexity and range of issues under study increases.

Where do we stand today in understanding the causes of autism? It is fair to say that researchers are developing a more complete understanding of the neurological factors associated with autism, but some degree of modesty is also appropriate with respect to the predictions that can be made or confidence with which particular neurological findings can be said to characterize autism. Many neuroscientific studies focus on specific aspects of the brain. Therefore, different aspects of the brain have been studied in different samples; there is seldom concrete evidence that these samples are very much alike, or that they represent a larger group of children with autism. This points out the need for independent researchers to conduct studies with other samples, to verify that the findings with one sample also apply to others.

In addition, many neuroscientific studies include small numbers of subjects. As a result, such studies are not able to detect relatively subtle but consistent differences that may exist between individuals who have autism and those who do not, and the studies may not be representative of children with autism more generally. Advances in research design, including identification of subjects with better measures, are addressing these limitations. Neuroscientific knowledge about autism is steadily advancing, but there are, nonetheless, considerations that affect the strength of the conclusions that can be drawn today.

One must also consider that the group of children diagnosed with autism is heterogeneous: some also have diagnoses of mental retardation, while others don't; some have seizure disorders, while others don't; some manifest regression or loss of attained skills, while others did not. Although there is a strong (and warranted) presumption that genetic factors play a strong role in the occurrence of autism, the heterogeneity of children with the condition and current research findings suggest that the relevant genetic factors are complex and multiple in nature. At this point one may reasonably argue that the behavioral condition of autism and ASD are final common pathways, or results, of differing genetic factors—that there is no single genetic factor that accounts for occurrence of the condition. Events prior to birth have also been implicated by neuroscientific studies. It may also be that in some cases, environmental events, such as reactions to toxins, may play a role. It may be that all of these factors, and others, are involved as risks or causes.

The Scientific Method

1. Observe and describe a phenomenon or group of phenomena.
2. Formulate a hypothesis to explain the phenomena.
3. Use the hypothesis to predict the existence of other phenomena, or to quantitatively predict the results of new observations.
4. Perform experimental tests of the predictions.
5. Modify the hypothesis based upon the test results.
6. Repeat steps 4 and 5.
7. Replicate the tests by several independent experimenters and properly performed experiments.



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RESEARCH REVIEW

Outcomes of Behavioral Intervention for Children with Autism in Mainstream Pre-School Settings

Title of article

Outcomes of Behavioral Intervention for Children with Autism in Mainstream Pre-School Settings.

Reviewed by: Kathleen Moran, MA, Caldwell University

Why this topic?

An intervention for young children with autism that has been identified as “well established” is Early Intensive Behavioral Intervention (EIBI). EIBI is based on the principles of applied behavior analysis and is implemented by trained specialists in a one to one format. This intervention has been shown to increase cognitive and adaptive functioning and possibly reduce autism severity. Although many behavior analysts recommend conducting EIBI programs in the child’s home, research shows the intervention can be effective in a variety of settings. However, there is still a need to determine if EIBI is effective within a more typical setting on a larger scale, such as a mainstream preschool.

What did the researchers do?

The researchers compared outcomes on measures of intellectual functioning and adaptive functioning in children who received two years of EIBI within a mainstream preschool program or treatment as usual (TAU). The EIBI group included 31 children with autism. EIBI staff were supervised and trained by a Board Certified Behavior Analyst (BCBA). Training included workshops, weekly consultations and team meetings to review individual programs, explanation and modeling of all programs, and training sessions with feedback. Teaching procedures were based on the principles of applied behavior analysis and implemented by trained staff in a one to one format, with the goal of moving to a group setting with peers of typical development.

In the TAU group, 12 children received an eclectic intervention that included elements from a variety of interventions such as: alternative and augmentative communication, applied behavior analysis, total communication, sensory motor therapies, TEACCH, and personal experience. A special education teacher provided supervision and consultation one to two times a week. Each child had a different agency responsible for the supervision and training.

What did the researchers find?

The researchers found that the 31 children in the EIBI group made significantly larger gains in intelligence functioning and adaptive behavior than the 12 children in TAU. Changes in adaptive behavior occurred primarily in the communication and socialization domains. Individual scores were assessed

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for statistically reliable change. Only children in the EIBI showed a reliable change, with 19.4% of children (6) making reliable gains in IQ and 6.5% (2) in adaptive behavior.

What were the strengths and limitations of the study? What do the results mean?

Overall the study showed that EIBI within a mainstream preschool leads to a positive change in intellectual functioning and adaptive behavior in children with autism. Compared to TAU, EIBI can be effective in a typical community setting. There are, however, some limitations, notably a small number of outcome measures, no data on the number of TAU intervention hours or the specific time spent on each intervention type, and lack of data on generalization and maintenance.

Results of this study show that EIBI can be effective when delivered in a community setting; however, research should assess the feasibility of implementing EIBI effectively in multiple community settings simultaneously. Potential barriers include the difficulty of fulfilling the recommended hours, competing demands on staff and the requirement for extensive, ongoing supervision of staff, child progress, quality of intervention, and program structure. Future studies should also include additional outcome measures to assess changes in language or features of autism, and to evaluate the generalization and maintenance of skills. In addition, program variations such as level of parent involvement and amount of intervention are important to investigate.

Eldevik, S., Hastings, R. P., Jahr, E., & Hughes, C. J. (2012). Outcomes of behavioral intervention for children with autism in mainstream pre-school settings. *Journal of Autism and Developmental Disorders*, 24, 210-220.

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

What did you do this summer? One young man's effort to make a difference.

By Melissa Taylor, Pennsylvania Training and Technical Assistance Network (PaTTAN)

While most 13-year-olds ride bikes and play video games, we caught up with one who was more interested in raising money for the Association for Science in Autism Treatment (ASAT). We are proud to feature him and his efforts in this issue of our newsletter.

Vaughn is a 13-year-old middle schooler at Tinton Falls Middle School in New Jersey. While he does enjoy many of the things other middle schoolers do, he also loves to be intellectually challenged, and was on a mission to be accepted into the National Junior Honor Society at his school. He began learning about autism and the misconceptions that exist about people living with autism and was unhappy to learn about the negative. He resolved to do his part to help change the conversation. He opted to raise money to support autism awareness and best practices to fulfill the leadership portion of his requirements for acceptance into the National Junior Honor Society.

He explored a number of organizations while searching for a beneficiary for his efforts and came across www.asatonline.org. On our website Vaughn learned about the resources that ASAT provides to families and professionals and decided to support ASAT.

Vaughn independently worked on all phases of his project, from the countless hours planning to selling his baked goods door to door; peanut butter rice crispy treats, red velvet cupcakes, and strawberry cookies. His plan was an enormous success, resulting in an impressive \$500.00.

ASAT is grateful to Vaughn and his efforts.

**Thank you for your support and for being an
inspiration to so many young people!**

