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For further information, please contact CCBS at center@behavior.org or plaud@behavior.org.

ABA and us: One parent's reflections on partnership and persuasion

Catherine Maurice

I would like to take this opportunity to do two things: Reinforce your understanding of how important is your work to so many people, and offer some fairly humble, common sense suggestions as to how you might improve the transmission of your work into the public domain.

For those of you who have not read my book, *Let Me Hear Your Voice*, I would like to take a moment to provide a context for how I, a Ph.D. in what your colleague Dr. Richard Malott referred to as "Literary Criticism or some equally irrelevant topic" find myself addressing a convocation of Behavior Analysts. The answer, in one word, is autism. I would also like to say at the outset that I know that Behavior Analysis has implications for many aspects of the human condition besides autism. But autism is what my family experienced, so I will speak about what I know best.

In December of 1987, I was the mother of Daniel, aged three, Anne-Marie, aged twenty-two months, and a newborn son, Michel. Around this time, it was becoming increasingly evident to me that Anne Marie was no longer using the 15 or 20 words she had previously acquired. She had odd head posturing and finger flexing. She had no appropriate play. She would pick up pieces of dust, and stare intently at them for long moments. She cried incessantly, or stared mutely into space with a blank expression on her face. Other than responding to a few food words, she gave no evidence of understanding language. She no longer pointed, no longer shook her head no or nodded yes, no longer said mama, or daddy, no longer smiled. The rate of her deterioration seemed to be increasing daily.

My husband and I took her to five of the most well known authorities we could find, who included pediatric neurologists, psychiatrists, and psychologists. One after the other, they pronounced their opinion.

1. "Pervasive developmental disorder: infantile autism"
2. "Pervasive developmental disorder with characteristics of the syndrome of infantile autism"
3. "Diagnostic Impression: Probable Autistic Disorder"
4. "Infantile Autism"
5. "Pervasive developmental disorder - not otherwise specified"

In 1987, the prognosis for infantile autism was this: Lifelong, severe, incurable.

What I have just presented to you are the facts, described in a more or less objective language. Those facts convey nothing of what can only be called the anguish of this time. They can't convey the searing panic as something begins to steal your child away from you. They don't even hint at the shock, the sleepless nights, the dry throat and pounding heart, the physical invasion of grief and fear.

But the point here is not to dwell on grief, which is mercifully past, but to underscore that objective language can never convey the whole of reality - a point to which I'll return momentarily.

Two years later, Anne-Marie's brother, Michel, who was so beautiful when he was born that his father and I had wept

as we held him in the delivery room, received the same series of diagnoses. He was twenty-six months old and every bit as beautiful, but losing, day after agonizing day, all his words, his understanding, and his smile.

In *Let Me Hear Your Voice*, I chronicle all of this. I look at people who helped, and people who hurt. I look at the treatments out there that promise much and deliver little. I take the reader through my mistakes, my faulty decisions and my moments of understanding. I chronicle my husband's wisdom, my therapists' passion, and my children's sweet participation in the journey. And I take the reader through the intensive intervention that led, finally, to the recovery of our children.

Today, my daughter is thirteen years old, and in the eighth grade of a regular school, where she is doing fine, without intervention or special support of any kind. She has friends, she argues with me about clothes, and her chief embarrassment, of course, is me, especially when I open my mouth to say something in front of her peers, or, God forbid, actually sing in public.

My son, now almost twelve years old, is in the sixth grade. Similarly to his sister, his latest school report shows significant academic strength and good social interaction. How normal are they? The question, after a while, becomes absurd. How normal are any of us? The fact is that they no longer display any of the behaviors associated with autism, they are aware of their history, they are empathetic and engaging children. The question frustrates as well because, in the past few years, it has become apparent to me that no amount of data, school reports, or follow up evaluations will convince those who are determined not to be convinced.

So, rather than trying to convince anyone of anything, I prefer to ask a more important question: Just how did these two children, and scores of other children like them, go from point A to point B? How is it that such progress is possible, when we parents were informed, in absolute terms, that autism is lifelong, severe, and incurable? How is it that children, even when they do not recover from autism, can still prove that they are capable of learning, and growing, and functioning in the world, to an extent hitherto thought impossible?

The answer is: Through a lot of hard work by a lot of people, including, without a doubt, many of you.

Your discipline, Behavior Analysis, was the foundation of our intervention program for both children. In 1987, I knew nothing about ABA, and only had a vague idea of something called "behavior modification," which, to my mind, meant forcefully training children to perform various meaningless stunts, for which they would be duly rewarded or punished for non-compliance. Moreover, plenty of so-called experts gladly reinforced this caricature for me. Never would I have allowed such an atrocity in my house, were it not for two providential events:

The first was reading, in the *Psychology Today*, an article written by Paul Chance, entitled "Saving Grace." The article described the work of Dr. Ivar Lovaas and his 1987 experimental study, a study that examined the effects of intensive behavioral treatment on young children with autism. The article was compelling, without being sensational. It presented, in layman's terms, something that no one else seemed to be talking about: Outcome data. Unprecedented outcome data.

The second was watching a young woman, Bridget Taylor, then completing a master's degree at Columbia University, work with my daughter, using the techniques of Behavior Analysis.

The hope given to us by Paul Chance's article, and the power of Bridget Taylor's demonstration was enough to persuade us to give behavioral intervention a try.

And then gradually, I began to understand ABA more and more. I started to understand what it was: Not some dehumanizing control of people through a cynical manipulation of rewards and punishments, but rather the light of scientific exploration brought to bear upon behavior, and upon learning. At its best, a rational, empirical exploration of conduct, including human conduct, that was able to predict certain probabilities of behavior, based on certain laws of learning.

This is really the heart of the matter for me, my reason for speaking out in support of this approach. I would not be here today if I believed that the only contribution of Behavior Analysis was the recovery of my children. For what good would that serve, to trumpet a private triumph, when I know how fiercely some other families still struggle?

What I do know, what I have seen with my own eyes, is the significant difference that Behavior Analysis is making in other children's lives, and in the lives of adults as well. What convinces me to keep speaking out is not even that I know some other children who have achieved normalcy. Rather, it is knowing that Behavior Analysis continues to help those that do not

recover. As time goes on, I have seen many different rates of progress in children who are receiving behavioral intervention. I have spoken to parents whose children have been in therapy for five years and will probably continue to need some form of support for most of their lives. I've seen children who, after two years of intervention, are now enrolled in first grade with normal peers. And yet, I have seen very few of any of these parents abandon Behavior Analysis.

Why is this? Very simply, because Behavior Analysis has given them a model of effective teaching. It has truly empowered them to make a positive difference in their children's lives, even while they may be searching for other biomedical solutions. As one group of parents has put it, they do not know where each of their children will end up, but they are convinced that Behavior Analysis is helping each of them, now, to reach their fullest potential.

I think it's important that you hear about these parents and children. I think that sometimes, the field of behavior analysis, like so many academic and scientific disciplines, advances its knowledge base in tiny incremental steps. Perhaps, in your desire to perform those steps correctly and precisely, it might be hard for you to appreciate how significant those incremental steps can be to so many people.

But believe me, they are: Behavior Analysis does not have all the answers, but it has compiled, over fifty years, more credible data than any fad or fashion in the analysis and understanding of human learning. It is science-based and solid, rational and, when you want it to be, practical. It is helping real people out here to deal with some very real problems. Your work, however incremental, however narrowly focused, contributes to the whole, and the whole contributes to the welfare of your fellowman.

That's the good news. Unfortunately, you know as well as I that you're not communicating very well with the public. There is widespread misunderstanding and distortion of the approach. Dozens of pseudo-scientific books and articles out there describe it as child abuse, a squelching of the spirit, a crushing of the soul. Treating the symptoms and not the "root cause," whatever that might be; a denial of the self, cruel, manipulative, dehumanizing, punishing, controlling; etc. etc.

Moreover, even when people do not attack behavior analysis, they make glaringly ignorant statements about it, like "Oh yes, that's where they do discrete trials for forty hours a week." Or, "behavior management is for really low functioning kids."

How do you go about changing some of this misrepresentation?

I think, first of all, you have to collectively define your goals. Do you want to reach out to us? If your goal is to preach to each other, you're doing a good job. If your goal is to gain more widespread acceptance, at some point you're going to have to go out to the public, and invite the public to come to you.

What do you say when you reach out to people, and how do you say it? If I were you, my first priority would be to develop a brochure, explaining, in clear English, what Behavior Analysis is. When my daughter was diagnosed, I found virtually nothing that adequately explained the discipline to me. When I wrote my book, I had to write my own overview of Behavior Analysis in terms that I felt were clear enough. Today, I can go to my local bookstore and find twenty books on pregnancy, cardiology, asthma, etc. These books are written for the public, yet still manage to maintain their scientific credibility. Where are the popular expositions of behavior analysis?

Aside from basically explaining what behavior analysis is, I would let people know what it is not. It is not, for instance, training for compliance. It's not turning kids into robots. It's not feeding them candy all day so that they behave. The worst thing you can do is just ignore these negative stereotypes. Effective teaching means that you set your message into a wider context, and you inform people about the competing messages they may hear. Aristotle and Cicero knew that effective persuasion is the ability to adopt the perspective of your listener: to articulate his fears and hostility for him, and relieve his anxiety where you can.

Persuasive teaching also involves an understanding of why people might be attracted to other approaches: The promise of a quick fix, the miracle cure, anything to alleviate the anguish and the longing. I believe that we are morally compelled to speak out about therapies that have proven useless or harmful to children. However, even as we offer firm redirection, we have to remind ourselves to listen to the hurt and the need. Every treatment fad in autism, from the scandal of facilitated communication to the excesses of biological experimentation on children, is the result of desperate parental need, combined with irresponsible professional encouragement - or silence.

But rather than criticizing people for their choices, it's probably wiser to sympathetically analyze those choices with them. People seem less defensive when we take the time to hear them out before bombarding them with research and data and evidence. I think that generally speaking, in autism therapy as in life, it is only when people have had a chance to articulate their own convictions and fears and desires that they will allow you a little space to propose a different perspective, another point of view.

Every message that anyone teaches has to be framed within a context of competing messages and underlying world views: For instance, one of the underlying assumptions of behavior analysis is that scientific research, with its emphasis on that which can be observed and measured, can yield reliably objective information about phenomena. On the other hand, statements about feelings, thoughts, and emotions do not lend themselves readily to verification or confirmation. I try to teach people about this assumption, make it explicit for them.

However, such framing concepts have to be carefully thought about, and carefully articulated, because they can lead to caricature and hostility. Many people have the impression that behaviorists deny the existence of anything that might be called the soul or the spirit or even the emotional life. According to this popular caricature (or is it sometimes an accurate perception?), behaviorists hold that since the only thing that can be reliably described is observable behavior, the existence of anything that cannot be demonstrated empirically is unknowable, unprovable, and therefore, perhaps not "real."

Whoa! And does this lead to complications! Can I "prove" that I love my child? Probably not reliably through any empirical or behavioral analysis, but I still "know" I love my child. Can I prove that there is a God? Absolutely not, but I still choose to believe in God, and to hold a theocentric view of life. Treating such beliefs and convictions as sad delusions or symptoms of intellectual weakness do nothing to help propagate the message that behavior analysis has much good to offer the world.

So how do you, (or I, for that matter) defend the concepts of scientific accountability, reasonable standards of proof, and credible empirical evidence as the benchmarks of effective therapies for autism, without being drawn into no-exit debates about the reality of spirit, soul, emotions, or mind? Maybe by simply drawing a clear distinction between two kinds of knowledge; Knowledge that is subject to the laws of logic, to reason, to demonstrable proof in the real world, and beliefs that remains forever "unprovable" but some of which we may simply choose to hold? Then, when drawn into a discussion about one of those flaky fad "treatments" for autism, we can attempt to elucidate this distinction. Framed this way, upholding the standards of science becomes possible, even for those like myself who choose to believe in God, and, more importantly, the issue becomes somewhat clearer for parents, I think. When choosing a treatment for a child's autism, do we opt for a model based on faith, or reason? On religion, or on science? On emotion, or on logic?

Another part of my message would be how behavior analysis works when done correctly. I would try to show people the process, and not just the product. Most people have the impression that behavior analysis = discipline = punishment. That somehow, all of us who have used this intervention have simply forced out children into a kind of robotic compliance. (Gee, I must remind my children about that the next time we have a Saturday morning homework discussion. "I thought I had trained you to be a compliant robot!")

I think that all of us, both the parents who have chosen behavioral treatment for their children and the professionals who provide it, have to speak out strongly and frequently against this caricature. It is terrifying to hear the rage-filled rhetoric of the anti-ABA factions out there, who insist that anyone who applies behavior analytic principles in a therapeutic intervention is a child abuser, but if we do not explicitly correct these outrageous accusations, pretty soon there will be no providers left who dare offer their services. Be aware of the attacks, the distortions, the misrepresentations, and speak out. Of course behavioral treatment has the potential to be poorly applied by unskilled or unscrupulous providers - all treatments, including medical and psychological interventions, have such potential, and can be demonstrated to have on occasion caused more harm than good. But if we allow behavioral intervention to be stomped out because some therapists are incompetent, that is tantamount to abolishing medicine because some physicians don't know what they're doing.

Another basic message I would try to get out to the public is an honest discussion of the positive contributions of behavior analysis. It cannot cure all children from autism, but it sure can make a dramatic difference in the lives of many of them. Why are we whispering this over the back fence? If you don't believe some of the stories you hear, maybe you should visit The Princeton Child Development Institute, the Alpine Learning Group or the Connecticut Center for Child Development, and meet some of these kids yourselves. Setting aside the issue of recovery, just watching any of the children learn and interact in these environments can be breathtakingly beautiful. The organizations and publications devoted to ABA should be trumpeting

the progress of every single one of those children. There are all kinds of successes out there, many stories of courage and perseverance. Behavior Analysis is a pathway towards a genuinely richer and more productive life for many many people, and yet, sometimes it seems as though you are so cautious that you hide that truth from the world.

Those are a few of the messages I would try to get out. Now, let's touch on *how* you might convey these messages:

You might start by zapping all forms of condescension: Most professionals, including behavior analysts, are subject to the elitist assumption that no outsider is capable of understanding the principles and practices his or her field of expertise. But that's silly. If schoolchildren can understand the germ theory of disease, if college students can understand quantum physics, why should the fundamentals of Behavior Analysis be forever out of reach of the common man? If you want us to learn, you can teach us what we need to know to make the right decisions, advocate for the right services, and demand the qualified people. If you want us to learn, the question is not "Are they capable of learning it?" but "Am I teaching this well?"

Teaching well means, primarily, speaking in a language that people understand.

Please don't get me wrong: Behavior Analysis cannot abandon its precise technical language. Your language must be objective if it is to be accepted by the scientific community as credible. You can't abandon this language without abandoning the scientific basis of Behavior Analysis.

But if you want to teach the public, you cannot refer to their children as "organisms emitting responses to specified stimuli under an intermittent reinforcement schedule." That type of talk will absolutely guarantee that you will not win friends and influence people. Most parents will pay attention only to those who can speak about their children in caring terms. We need to hear some explicit acknowledgement of them as unique and precious human beings. How can any of that affiliation and sympathy be conveyed in a language that is exclusively objective and scientific?

The answer is it can't. You have to maintain your scientific discourse, but at the same time develop a parallel language, translating the jargon into plain English and teaching through clear analogies and concrete examples.

In order to write in this clear and sympathetic voice, you have to go to the mainstream media. The *Journal of Applied Behavior Analysis* is not the appropriate forum for this kind of writing. I have heard some of you speak a little scornfully of the popular press. And Lord knows it's true that one can find any kind of nonsense out there. But the popular press is a tool, like any other tool. It may be used or misused, but one thing is certain: it is a very powerful tool. The *Journal of Applied Behavior Analysis* has a circulation of about 2000 per year. *Reader's Digest* has a circulation of 30 million - per month.

So what's the answer, rush out and redraft all your articles for *Reader's Digest*? Obviously not. But again, maybe you could find a couple of people in your organization who know how to write for the popular press. The Internet is there, its enormous potential waiting to be tapped by anyone who will take the time to focus in on it. Don't curse these repositories of opinion and anecdote. Bombard them with credible research. Raise the consciousness of their readers. Put the issues on the table. The whole point is to bring the rigor of scientific thought into the popular media, not to proclaim the eternal gulf between science and the masses.

We will have no behavioral intervention for children with autism if we have no behavior analysts or behavior therapists. Please do everything in your power to encourage enrollment in undergraduate and graduate level programs, and to define national standards for such programs. This will ensure not only an increased population of behavior analysts, but will also begin to rectify some of the concern about competencies, qualifications, and celebrity cults.

And finally please support our organization, the **Association for Science in Autism Treatment**. We support research into all promising treatments for autism, biological or behavioral, and our Advisory Board is being formed to bring us the expertise of renowned geneticists, immunologists, and psycho-pharmacologists. Several parents on our Board would like nothing better than to find an alternative to the hard, expensive and time-consuming demands of the behavioral intervention they have chosen for their children. However, while we are all hoping for that day when an effective biological treatment or cure has finally been identified, our organization is committed to the children who are already here, and who desperately need effective services *today*. Therefore, an important branch of our mission is to do everything in our power to increase access to such science-based intervention for the families and children who need it now.

I'd like to sum up these remarks by asking you to think of the relationship between effective dissemination of a message, effective teaching, and being a loving parent. All three processes intersect with each other, share similar tactics. Imagine, for a moment, that you are parents, and you are trying to teach us kids out here something very important, very crucial.

How does a loving parent teach a child? He assumes intelligence in his child. He breaks down complex concepts into understandable terms. He explicitly recognizes competing and dangerous influences, arming the child with her own discriminatory tools to combat those influences. He uses every available medium to hammer his message home. He brings the message to the child, instead of waiting for the child to come to him. Above all, he set aside his own desire for worldly recognition, in favor of his child's well being, maturation, and eventual independence.

Why should you do all that for us? The answer is you shouldn't. You should do it for our children, who deserve every opportunity that human love and human intelligence can create for them. As the poet Stephen Spender has said:

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