

On Books

The Complete Guide to Autism Treatments: A Parent's Handbook: Make Sure Your Child Gets What Works!

Richard M. Foxx

Pennsylvania State University, Harrisburg

Few conditions have been as fraught with fad, controversial, unsupported, disproven, and unvalidated treatments as autism (Foxx, 2008). The underlying reason for this relates directly to science being misunderstood or ignored by parents, professionals, and paraprofessionals. Many people simply do not understand how science works, and this includes any parents and paraprofessionals with no scientific background. Many professionals also do not understand science, typically because their education featured no scientific training or it was greatly deemphasized. Unfortunately, this is the case for many of the professionals who work directly with children with autism. There are other professionals who understand science but choose or have chosen to ignore it for professional or monetary gain.

Sabrina Freeman (2007) recognized all of these factors and decided to do something to help. The result is *The Complete Guide to Autism Treatments: A Parent's Handbook: Make Sure Your Child Gets What Works!* Although the book is written for parents, professionals will greatly benefit either because they will now understand how to evaluate the science behind treatments or have a reference to give to parents. The book also would serve nicely in a graduate course on autism, ethics, or

behavior analysis. The piece de resistance is that Freeman is both the mother of a child with autism and an accomplished social scientist with a PhD from Stanford. Two of her other books, *Teach Me Language* (Freeman & Dake, 1997) and *Science for Sale in the Autism Wars* (Freeman, 2003), are directly related to autism and attest to the depth of her scholarship.

Freeman's gift is that she writes about what some view as complex subjects in simple understandable language. Indeed, she points out that the scientific method is not difficult to understand and that knowledge of it permits rational decision making when it comes to evaluating the next treatment or purported cure. Freeman's objective is to protect thousands of children from quackery while providing parents and professionals with evaluative tools for judging the effectiveness of a treatment.

The book is organized into two sections: "What Works and What Doesn't" and "How Do We Know What Works and What Doesn't." Section 1 is designed to produce informed consumers who will seek a treatment for their children because they know it has scientific validity. Anyone with a good background in science will find this section well done and extremely helpful. Those with little background in science are encouraged to read Section 2 first in order to have the background to fully appreciate the in-depth evaluations available in Section 1.

Correspondence may be sent to Richard M. Foxx, ABA Program, Pennsylvania State University, Harrisburg, 777 West Harrisburg Pike, Middletown, Pennsylvania 17057 (e-mail: rmf4@psu.edu).

In Section 1 every major treatment option is exposed to the following questions: What is it? What evidence do practitioners have that this really works? What does the therapy actually look like? Would I try it on my child? What else do I think? What additional studies would I like to see the researchers do in this field? Who else recommends for or against the treatment? So you are still on the horns of a dilemma? What's the bottom line? The answers are typically spot on, in this reviewer's opinion, and are consistent with Freeman's reputation as a tireless advocate for the rights of children with autism to receive science-based treatment. The literature review is exhaustive.

Under behavioral therapies, Freeman examines applied behavior analysis, intensive behavioral treatment (IBT) that is home or center based, school-based IBT and what she refers to as offshoots of IBT, including pivotal response training and the natural learning paradigm (PRT/NLP), positive behavior support (PBS), verbal behavior therapy, and fluency training. Freeman reports that she implemented an intensive home-based behavioral treatment program based on the pioneering work of Ivar Lovaas (Lovaas, 1987) and that her daughter, who is now an adult, made incredible gains. That said, she cautions readers that her anecdotal reporting of this outcome should not sway them to use the method, even if it comes from someone who respects science. Rather, she states that what should be convincing is the "abundance of *scientific* evidence behind the method" (p. 18) and it was just such evidence that led her to choose to use IBT with her child.

High-quality school-based IBT programs are supported by scientific research. Although all children benefited from these programs, the most significant gains were made by children who began treatment before the age of 5 years. Had she lived in New

Jersey when her daughter was young, Freeman would have seriously considered sending her to the Princeton Child Development Institute. The offshoots of IBT receive a fair evaluation based on the literature to date, and the kinds of studies suggested for researchers working in the various areas are excellent. Freeman's review finds PRT/NLP to be promising, but it does not have enough research evidence to suggest that it is globally effective in ameliorating the condition of autism. Based on the scientific research to date, verbal behavior therapy is described as an emerging treatment but not one that should be applied solely to ameliorate the symptoms or conditions of autism. A similar bottom line is given for fluency training, in that there is limited evidence that points to its appropriate use for certain deficiency characteristics of autism.

Freeman's bottom line on PBS is that "there is no evidence to conclude that PBS is anything more than a philosophy rather than a science. Consequently, there is no evidence to demonstrate that PBS ameliorates the condition of autism" (p. 59). She urges PBS researchers to abandon the antiscience, anti-intellectual discipline they have developed and return to the field of applied behavior analysis where they can compete with behavior-analytic researchers and "have their PBS research properly scrutinized and evaluated by their ABA academic peers" (p. 58). Her final point on PBS is that its literature makes autism appear to be an entirely different disability. In the PBS autism world, children "seem to be very mild, and the behavior problems are all easy to control, as long as the environment is 're-engineered.' Children with self-injurious behavior do not seem to be a challenge for this group" (p. 58). Her caveat is that perhaps the children in PBS studies are "not classically autistic" (p. 58). After reviewing the literature and based on living in a region where

PBS is used extensively by school districts and with governmental support, Freeman expresses her opinion that “positive behavioral support is a very dangerous field for children with autism” (p. 56). Her reasoning is that PBS is a kind of religion of political correctness that “denies children with autism access to proven, science-based treatment methods” (p. 56). She even finds the term “positive” attached to behavior support as offensive because it “carries a presumption that the PBS practitioner is different and apart from his ‘evil’ ABA behaviorist counterpart” (p. 57).

In the “Other School-Based Therapies” section, Freeman reviewed TEACCH, the Colorado Health Sciences Center playschool, Giant Steps (Canada), Higashi/daily life therapy, and the Walden preschool. Her bottom line is that there is not enough research evidence to date to conclude that TEACCH is an effective treatment or that the Playschool autism intervention substantively improves the condition of autism. She finds insufficient evidence that the Higashi school or Walden preschool have an effective curriculum for decreasing the symptoms associated with autism or treating and educating children who have it. She found no evidence in support of Giant Steps.

The “Child-Led/Parent-Facilitated Therapies” section includes the floor-time (Greenspan/developmental, individual difference, relationship) model (DIR), Options Institute/Son-Rise program, relationship development interventions (RDI) and the Learning to Speak program. Two therapies, DIR and RDI, had not generated enough scientific evidence to conclude that they were effective treatments for children with autism. There was no evidence in support of Son-Rise and the Learning to Speak programs as effective treatments. Freeman had personal experience with DIR a number of years ago, because she chose it for her child when she was first diagnosed. The

DIR philosophy, which turns everything the child does into a social interaction, was personally very appealing, and this treatment was being offered by the psychiatrist who had diagnosed her daughter. Soon after, Freeman abandoned DIR because, despite its personal appeal, there were no data to support it. Her bottom line was “my child was wasting her time and I was wasting my money” (p. 139).

The biomedical therapies are familiar to many parents of children with autism. They include the diet and nutrition therapies of gluten- and casein-free diets, the candida diet, the nutritional deficiency diet, the ketogenic diet, chelation therapy, intravenous immunoglobulin therapy, secretin therapy, and Vitamin B6 and magnesium therapy. Although these theories have been around for 30 years, none have any independent scientific support. Until there is, Freeman regards their use as pure experimentation on a child.

Chelation therapy consists of removing harmful metal toxins from the body by introducing chelating agents into the body. These bind with the metal ions and then are expelled. Chelation is a recognized treatment for children with lead poisoning but not for children with autism, who do not have chronic heavy metal toxicity. Although many fad treatments are costly in terms of money and time lost, chelation can lead to horrible medical complications, including death. Freeman’s bottom line is chilling. Chelating a child with no signs of heavy metal poisoning is engaging in high-risk experimentation. There is no evidence to support chelation as an effective therapy for children with autism.

There is not enough evidence to support any type of diet and nutrition therapy as an effective treatment for improving the symptoms that characterize autism. Unfortunately, parents are drawn to these approaches because they are something the par-

ent can control and follow, and they fit with the parent's role of nurturer and provider of sustenance. Joining diet and nutrition interventions as pure experimentation are intravenous immunoglobulin therapy, secretin therapy, and Vitamin B6 and magnesium therapy. Although Freeman is never shy about expressing her opinion based on her review of the literature, she always provides a list of public and private agencies that recommend against a treatment or state that it failed the scientific version of the sniff test.

The speech and language therapies include the Fast ForWord program, the Hanen method, Lindamood-Bell learning processes, and the SCERTS model. None of the four have any evidence to support their use as effective treatments to improve the language impairment associated with autism or ameliorate its symptoms. Freeman would especially like to see the developers of the SCERTS model test their protocol against its main competitor, intensive behavioral treatment. She makes this suggestion for a number of therapies, especially those that are critical of intensive behavioral treatment.

The miscellaneous therapies section is a veritable rogues' gallery. All of the classic fads are present, including auditory integration training, craniosacral therapy, dolphin-assisted therapy, facilitated communication training, holding therapy, sensory integration therapy, and vision therapy. Others on the list include art therapy, music therapy, and pet-facilitated therapy. Because art and music therapies are regarded as relatively harmless and not prohibitively expensive, most professionals tend to give them a pass when harmful interventions are discussed. Art therapy has no evidence of support, and there is not enough evidence for music therapy to be considered an effective treatment for the symptoms of autism. Freeman recommends removing the term *therapy* from

music, and I would add art. Some children with autism enjoy music and art, and they can be used as reinforcers and for training in leisure activities. In this limited role, both can have a place in a child's program.

Although a dolphin ride may be reinforcing for a child with autism at the Dolphin Center (\$2,000 per week for 1 to 3 weeks of treatment), there is no scientific evidence that it is an effective treatment. This type of therapy fits in the category of those that are essentially ignored by scientists, because it is seen as not harmful but simply expensive. And, it is not the type of day-to-day therapy that would replace an effective intervention like applied behavior analysis. It is best used by parents who have money and like salt-water vacations.

Freeman's advice regarding pet-facilitated therapy is that "there is no downside risk to owning an obedient, loving dog" and "the experience may be great for your child; however, do not expect therapeutic results" (p. 332). Given that there is insufficient evidence to conclude that this therapy is effective, a dog from the pound will serve as nicely as a costly, specially trained therapy dog.

Vision therapy and craniosacral therapy are not commonly used for individuals with autism, although they are recommended for other conditions, ailments, diseases, and disabilities. There is no evidence or insufficient evidence to recommend either for autism or any other problem. Quackwatch (a leading Web site designed to expose harmful therapies) has craniosacral therapy on its list of nonrecommended treatments. The use of vision therapy for children with learning disabilities, in the form of eye exercises or specially tinted glasses, is not supported by any pediatric or pediatric ophthalmology professional academy.

Much has been written criticizing and condemning auditory integration therapy, facilitated communication training, holding therapy, and senso-

ry integration therapy (Jacobson, Foxx, & Mulick, 2005), and Freeman continues the practice. These therapies are particularly insidious because they take valuable time away from effective therapy and are highly seductive for parents who desperately want to help their children with autism. Auditory integration therapy is not only ineffective; it can be very costly. I know of several situations in which parents who could ill afford to do so have spent thousands of dollars on this treatment. Holding therapy is psychoanalytically based and has followed the general course of psychoanalysis in the U.S., which is to say that it has fallen out of favor over time and is most likely to be practiced or implemented in New York City. It has gone the way of Bruno Bettelheim, refrigerator mothers, and the notion of a child with autism having “attachment issues.”

Sensory integration therapy has been a boon to occupational therapy, because the underlying premise is that autism is a form of sensory dysfunction. Although there is little or no evidence regarding its efficacy, countless children with autism receive it in school as a legally mandated part of their individualized educational program. Parents like it because a sensory intervention that is designed to address a child’s neurological needs has just the right amount of mind–body feel. Children seem to like it because having a perky occupational therapist brush your arms, push you on a swing or merry-go-round, or squeeze your arms is a pretty good way to spend a “treatment session.”

In the hall of shame of fads and autism, nothing ranks higher than facilitated communication. This therapeutic intervention is proof positive that H. L. Menken had it right when he said that “No one ever went broke underestimating the intelligence of the American public.” It would be bad enough if facilitated communication were simply worthless and

costly, but it also carries risks for parents and guardians, given the number of them who have been falsely accused via facilitated communication of sexually molesting their children and charges. Anyone whose child is receiving facilitated communication is just a disturbed facilitator away from being charged with a sex crime.

On a positive note, there is some evidence that exercise therapy may have some limited, short-term effect on the stereotypic behavior of individuals with autism. And, no one can argue that engaging in exercise is not good for all of us, especially those prone to obesity. Freeman endorses incorporating exercise into a child’s daily life, but cautions that any programmatic efforts should involve a behavior analyst, objectives, and some data monitoring so that valuable therapeutic time is not wasted.

Section 2 provides the basic rules and tools that enable one to evaluate the autism treatments described in Section 1. Freeman goes beyond the scientific method to look at how science is funded, how bias can slip in, the politics of research, and what constitutes pseudoscience. Her goal in this section is to inoculate parents from incompetent researchers or illegitimate purveyors of autism treatment in order to protect their children from the quackery that is pervasive in autism.

Freeman meets this goal admirably. She begins the section by asking “Why care about science?” followed by a discussion of “experts and researchers” that the readers of this journal will recognize as a Brandisian lifting the rock and letting the sunshine in. Although autism researchers and experts know what Freeman is telling parents here, most have been reluctant to share it with those outside our inner circle. For example, Freeman cautions that “there are some very intelligent, talented researchers who produced biased research which they often have pub-

lished in peer-reviewed journals” (p. 384). Her discussion of the world of academic publishing is revealing on multiple levels. Consider these topical headings: “Advancement Trumps Quality Concerns,” “Peer Review—Necessary But Not Sufficient,” and “Uncover the Funding Source for the Study.”

A mini course in experimental design is included that discusses the advantages and disadvantages of between- and within-subject designs, factorial designs, and single-subject case designs. Freeman’s discussion of how studies become biased and how to avoid it is excellent, as is her treatment of the different types of bias. Being a social scientist, Freeman knows her way around the waterfront when she illustrates how researchers mistakenly ruin their own well-designed autism treatment studies. She concludes the book with red flags for quackery.

This book is a must read for any parent who has a child with autism, because within its pages lies the unvarnished truth regarding what works and doesn’t work and how to make the distinction. If you work with parents, encourage them to buy a copy. If you work at a school or agency, make sure this book is in the library. If you teach behavior analysis, use the book to expose your students to an author whose writing is elegant, straightforward, and brutally honest.

For a true understanding of the source of the passion that drove Freeman to write this book, read *Science for Sale in the Autism Wars* (2003) that describes a landmark legal battle between families with children with autism and government and academic mercenaries. Although I would never wish for anyone to go through what Sabrina Freeman has experienced in her lengthy fight to have science be applied to her daughter, she took her disappointment and rage and turned them into two very thought-provoking books for which parents with children with autism and those of us who treat them should be very grateful.

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