

Autism Resource Guide

*for families of newly diagnosed
children*



ASAT Real Science, Real Hope

ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

Introduction

The Autism Resource Guide is a collection of helpful information for families of children recently diagnosed with autism spectrum disorder. For those parents who are brand new to the field of autism and its treatment, and are in immediate need of basic information and direction, we suggest go to Resources and Books for Parents first.

The guide is organized into three sections: Articles, Reviews, and Resources and Books for Parents.

In the **Articles** section, parents can read about tools they can use to investigate treatment options, to scrutinize information from the marketers and the media, assess a treatment's authenticity and validity, and evaluate a behavioral provider.

In the **Reviews** section, ASAT presents a summary of key publications with the purpose of assisting parents in becoming savvy consumers of autism information, research, and treatments.

In the **Resources and Books** section, ASAT lists useful websites and books for all parents but especially for those parents who need access to resources immediately, as mentioned above. Parents shouldn't be lured by under-researched treatments. The Autism Resource Guide can help parents learn how to support real science in autism treatment.



Our Mission:

We promote safe, effective, science-based treatments for people with autism by disseminating accurate, timely, and scientifically sound information, advocating for the use of scientific methods to guide treatment, and combating unsubstantiated, inaccurate and false information about autism and its treatment.

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Articles

The Road Less Traveled: Charting a Clear Course for Autism Treatment

David Celiberti, PhD, BCBA
Suzanne Buchanan, PsyD, BCBA
Felicia Bleecker, PsyD
David Kreiss, PsyD
David Rosenfeld, PsyD

We believe it is important to provide parents and caregivers of children with autism with a step-by-step approach to the investigation of treatment options, thereby enhancing their chances of making the most informed and effective decisions for their child. It is our view that the scientific practices and high standards used within Applied Behavior Analysis (ABA) offer all of us very useful tools for negotiating the variety of treatment approaches available in the field.

We recognize that our readers possess varying familiarity with ABA. Many may not be aware that the assessment and evaluation methods utilized within ABA can actually provide parents with a useful way of exploring various treatment choices for their children.

- We can identify and clearly define the behaviors that we wish to target for change.
- Once a definition of a target behavior is created, we can track the frequency, intensity, and/or duration of the target behavior's occurrence before the treatment is ever implemented (baseline data). If it is not known how frequently the target behavior occurred before treatment, it will be impossible for us to assess the effectiveness of the treatment in increasing or decreasing the behavior.
- Next, we can collect data on an ongoing basis as the treatment is implemented to observe trends in the target behavior. Are behaviors increasing, decreasing, or remaining unchanged?
- After the treatment has been implemented for a sufficient amount of time, we can make a determination regarding the effectiveness of the treatment. At this point, it may be necessary to maintain, alter, or discontinue treatment.

These evaluation procedures above are integral components of interventions based on ABA and are routinely carried out within well-run ABA treatment programs. However, all interventions should be subjected to the same scrutiny when it relates to something as precious as the safety, well being, and potential of an individual. The responsibility to objectively assess progress should not diminish with the implementation of alternative treatment

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options. In fact, interventions that lack a sound body of scientific support should actually be evaluated even more rigorously.

We have included a series of questions for consideration when evaluating treatment approaches for autism. It is followed by a summary of the key questions that can readily be used when interviewing prospective service providers including those who offer ABA services and those who do not. Information gathering and decision-making can be a sequential process:

- Phase I explores whether the intervention in question is a viable, safe, and potentially worthwhile intervention. Published scientific evidence will likely address many of the questions included in this phase of inquiry. More specifically, when looking to published research for these answers, the introduction section of the research article will be most helpful as it lays out the research that supports and leads up to the current study.
- Phase II explores whether the intervention in question is appropriate for an individual with autism and whether the service provider is suitable. When looking to published research for these answers, two sections of an article will be most helpful: the method and discussion sections. The method section describes the participants. To the extent that an individual is similar to the participant in the study, it is reasonable to expect that he/she may have a similar response to that particular treatment. The discussion section of an article lists the contributions and limitations of the treatment and the study itself.
- Phase III describes assessing outcomes objectively and whether the risks are outweighed by the potential benefits. The results and discussion sections of a published research study provide helpful information to answer these questions regarding target behaviors (often called the dependent variables), how the target behavior is measured, the amount of behavior change, and an analysis of the advantages and disadvantages of the intervention. In the absence of published scientific evidence that a particular intervention is effective, consumers must be particularly cautious and these questions should be considered even more carefully.

Phase I: Exploring the viability and appropriateness of a treatment approach

Research

- First and foremost, what research is available in the professional research literature that confirms the effectiveness of this approach? Is there research that does not support the effectiveness of this approach?

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- In the absence of published research supporting the effectiveness of this approach, how do the proponents of the approach justify their advocacy in the face of no published scientific support? (See Green, 1996a)
- What percentage of individuals with autism has experienced positive effects with this treatment approach? Are there any characteristics that differentiate the individuals who have experienced positive effects from those that have not?
- How important are these positive effects? Are they statistically significant (i.e., not due to chance)? Are they clinically significant (i.e., observations suggest a noticeable and desirable change in one or more important area of concern)?
- Do the results appear in published research, or are they presented as estimates in a case study or narrative report? What is the size of the group upon which these estimates are based? If they are estimates, who are they based upon?
- Does the published literature represent objective, empirical research (i.e., scientifically driven and data-based)? Or is it descriptive research that describes someone's impressions over time?
- What is the theory/rationale that drives this treatment approach? Does this theory make intuitive sense? Does this theory have scientific support?
- Are there individuals examining this approach who are committed to science-based research? How many researchers are currently investigating this treatment approach?
- How can this supporting literature be obtained?

Treatment

- What areas of functioning and specific behaviors are being targeted by this approach? In other words, how exactly does this treatment impact upon individuals with autism?
- How does this treatment approach work? Is there a planned and documented sequence of assessment and intervention strategies?
- How will skill gains made in treatment sessions generalize to everyday settings in a functional manner?
- What are the risks and benefits of this treatment approach? Do the potential benefits

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outweigh the risks? Are there other approaches that may provide the same benefits with fewer risks?

- Are there adverse effects associated with this treatment approach?
- How long has this approach been available?
- Are there multiple service providers with whom this treatment approach can be discussed?
- Are there schools and agencies utilizing this particular approach that are committed to science-based treatment?
- What are the criticisms and limitations of this treatment approach?
- How have the criticisms and limitations been addressed by providers/supporters of this approach? Are responses to such criticisms complete, sound, and objective, or are they vague and defensive?

If this treatment approach appears to be a viable, safe, potentially worthwhile intervention that has sufficient scientific support, then Phase II questions should be explored. If unsatisfactory responses are obtained, if multiple incomplete responses are offered, or appropriate answers could not be located, then consumers are discouraged from pursuing the approach in question.

Phase II: Assessing the appropriateness of the intervention under the supervision of a specific service provider for a specific individual with autism

- Why is this specific individual with autism a good candidate for this treatment approach? Upon what information is this determination based (e.g., analysis of immune functioning, behavioral observation, data from blood work, standardized testing)?
- Does every individual with autism receive the exact same treatment? If not, how will this treatment be individually tailored and based on what factors? In other words, how can this treatment approach be adjusted to meet the needs of the specific individual?
- How does this approach fit in with the individual's existing treatment? Can it complement existing interventions? Is it compatible? Is it counterproductive or will it interfere with the existing treatment? In what ways? How can such interference be prevented, avoided, or minimized?

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- What are the necessary credentials and experiences to carry out this treatment approach safely and effectively? Does the potential service provider have the necessary credentials and experiences to carry out this treatment approach safely and effectively?
- Is there a system of procedural safeguards providing oversight and accountability for this service provider in the case of malpractice? (Examples include licensing and certification boards.)
- How does this treatment approach as it is outlined in the available research literature differ from the actual treatment approach used by the service provider?
- How costly is this treatment approach for the specific individual? In terms of financial resources? In terms of time accessing services? In terms of disruption to other services? In terms of parental effort? In terms of impact on family life?
- What are the start-up expenses? What are the ongoing expenses? Will the expenses be covered by insurance? Will the expenses be covered by the school district (if the individual with autism is enrolled in school)? Are there external sources of funding for this treatment approach?
- What is the parents' and caregivers' role in implementing or supporting this treatment approach? What support or oversight is needed?
- What is the school's role in implementing or supporting this treatment approach? What support or oversight is needed?

If it has been decided that this treatment approach may be appropriate for the specific individual with autism and a particular service provider is suitable to offer the treatment approach, then proceed to the Phase III questions. If the potential provider is not able to answer questions satisfactorily or does not have the necessary credentials or experiences, then another provider should be sought and Phase II questions should be reconsidered. If it appears that the individual with autism is not a suitable candidate, then consumers are encouraged to explore other approaches or continue their inquiry with another provider (to obtain a second opinion).

Phase III: Monitoring the implementation of the treatment and evaluating effectiveness

- How will success be measured for the specific individual?
- What specific areas of behavior or physiological functioning are being used to measure effectiveness? Have these areas been defined objectively, clearly, and concisely?

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- What baseline data are requested by the service provider (i.e., information collected prior to an intervention in order to provide an objective standard for evaluating change)? This is an important question to ask because many service providers fall short in this area.
- Does the service provider discuss ongoing data collection? If not, how does the provider anticipate making an objective judgment about the success of the intervention in the absence of data?
- Does this treatment approach lend itself to a reversal (i.e., the treatment is briefly discontinued to see if the rate of target behavior returns to original levels)?
- How will the service provider measure the effectiveness of the intervention if there are concurrent interventions that may be targeting the same areas (i.e., other interventions occurring simultaneously)? How can unique contributions of the concurrent interventions be determined?
 - Do the potential positive benefits outweigh the costs?
 - Are there any potential side effects that should be anticipated for this individual? How should the side effects be managed? Which side effects warrant a call to the service provider? Which side effects warrant immediate discontinuation of the treatment?
 - What will the length of this intervention be for the individual? What time period is necessary for this approach to begin to show positive effects?
 - How frequently does the individual need to be seen by the service provider? What will the re-evaluation involve?
 - At what point can one expect to stop this intervention? How will it be discontinued or faded?
 - How frequently does the parent need to communicate with the service provider? What kind of information should the parent be reporting to the service provider?
 - What should the school's role in monitoring this treatment approach be, if any? Would there be any benefit to restricting information about the intervention regarding the intervention to only a select few staff persons (i.e., in order to minimize a biased evaluation of change)?

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Conclusion

The above list of questions is not intended to be exhaustive, nor is it necessary to use the entire list when exploring alternatives. Instead, this list is provided in the hopes of expanding the range of considerations available to parents and caregivers when pursuing any treatment approach, even an approach that enjoys significant scientific support such as ABA. Parents who possess greater knowledge and a framework for evaluating treatments can feel more confident in making sound treatment decisions. As consumers of these services and perhaps the strongest advocates for their children's safety and well-being, parents have not only the right, but also the responsibility to protect their children. Parents and caregivers should be informed as to what they can expect from any given treatment and should be knowledgeable about whether there are any potential risks associated with that treatment.

Professionals who offer or market interventions to individuals with autism have the obligation to fully explain their treatment methods, to clearly identify the nature and range of possible treatment effects, and to provide a means for evaluating the effectiveness of their interventions objectively. Professionals should not be offended when asked such questions concerning their services, and parents should not be made to feel intimidated for seeking such information.

We look forward to the day when parents need not work so hard at sifting through the enormous number of approaches available and when service providers have a broader array of scientifically-validated procedures to draw upon when addressing the many needs of children with autism. It is hoped that by empowering parents with the tools needed to negotiate the maze of interventions and to be more knowledgeable consumers, the quality of services available to individuals with autism will be enhanced and the road to effective treatment will be clearer.

Autism Awareness and the General Public

David Celiberti, PhD, BCBA

What should the general public know about autism treatment?

Even though autism spectrum disorder (ASD) is no longer rare as it once was, each person with ASD is unique. Efforts to help his or her realize his/her fullest potential should be individualized to meet specific across settings such as home, school, community, and the workplace. These efforts should also be informed by input from the individual, as well as his or her family.

Do not believe everything you hear. There are dozens of supposed "miracle cures" and "breakthroughs" for ASD which receive widespread media attention, even if they have not been proven effective. Sadly, successful treatments rarely gain media attention.

On a related vein, do not believe everything you read. Not all information on the Internet is reliable and accurate, and celebrities are neither trained nor equipped to define or guide ASD treatment, even though many appear comfortable in that role. On the other hand, there is a large body of research published in peer-reviewed scientific journals which should guide autism treatment. Visit our website to learn more at www.asatonline.org.

Lastly, there is hope and tremendous opportunity. With the right treatment, individuals with autism can lead happy and fulfilling lives. Research indicates that interventions such as applied behavior analysis (ABA) can effectively help children and adults with ASD realize their fullest potential. Early and intensive behavioral intervention can make a huge difference, both with respect to human potential and significant cost savings across the lifespan.

How can the general public make a positive difference?

It cannot be overstated that it takes a village to help individuals with ASD learn to enjoy and benefit from all that their communities have to offer. Every member of the public can make a difference in supporting individuals with ASD and their families. There are so many positive ways the public can help. Although I will share several examples here, this list is by no means exhaustive:

1. If you have a family member or a neighbor who has a child with ASD, ask specifically how you may be helpful (e.g., assist with siblings, offer play dates, help with transportation to therapies, or provide an empathic ear).

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2. If you see a family struggle in the community, do not stare, comment, or judge. In some cases, it may be appropriate to go over and assist (e.g., “I see you are helping your little guy, may I help you put your bags in the car?”). Family members may take you up on your kind offer or may just decline.
3. If your children are interested, inquire if there are opportunities for them to help classmates with ASD at their school (e.g., becoming a lunch buddy or a peer tutor). This is particularly beneficial in the later grades when opportunities for students with ASD to interact meaningfully with their typically-developing peers are lessened.
4. At school board meetings, encourage board members to learn about best practices in special education that are scientifically validated. Inquire if special education resources are being spent on interventions that lack scientific support or are not being spent on those that do possess such support (e.g., ABA). In fact, a research basis should inform all decisions.
5. Some faith communities are very welcoming to families of individuals with ASD, whereas others are not. Discuss this with your place of worship. Identify steps that can be taken to help individuals with ASD participate in their religious communities in a positive and meaningful manner. This applies to both religious ceremonies, as well as day-to-day participation.
6. Encourage organizations to be more accepting of persons with ASD, and to take appropriate steps to learn how to create meaningful inclusion opportunities (e.g., seeking out information, soliciting training and education, learning from others who are doing this with success).
7. If you are involved with youth sports or other extracurricular activities, offer to coach and/or mentor a player with ASD.
8. Encourage your town or city to provide and/or create recreational opportunities that include individuals with ASD as there is often a tendency to focus only on separate experiences for those with ASD.
9. Educate the business community about possible employment opportunities for individuals with autism
10. Support ASD organizations that put science first. Research how your donations are used.

Key Elements of a High Quality Education for Students with Autism

David Celiberti, PhD, BCBA-D
Renee Wozniak, PhD, BCBA-D

A high quality education would include the following elements:

- Be truly individualized - An educational plan should truly fit the student with autism like a glove fits a hand. Services should not be about what a provider likes to do, but rather what the student needs, as determined through ongoing, valid assessment. The largest area of need should be given the greatest attention with respect to the number and distribution of goals.
- Be comprehensive - A high quality education targets the full array of skills that will promote success at home, school and community and uses a wide range of techniques based on science that are well fitted to the skills being targeted.
- Keep the future in mind when selecting goals - The skills needed to be successful, independent and marketable in the next setting (be that a particular job or a particular 4th grade classroom) must be identified and addressed.
- Use well conceptualized behavior management strategies - When addressing challenging behavior, these strategies should take into account the underlying function of the behavior, include carefully selected antecedent- and consequence-based supports, and build skills to help students better meet their needs in a way which promotes their day-to-day independence and opportunities.
- Consider and offer inclusion opportunities carefully - Ensure that it occurs with the appropriate supports and is delivered by adequately trained staff. The benefits of inclusion do not occur through pure exposure alone; rather, skill acquisition occurs when inclusion is approached as a systematic, individualized process, with proper supports, ongoing monitoring of data, and a goal of challenging the student with autism while not overwhelming him or her or inadvertently creating isolation.
- Carefully implement instruction, including modifications and accommodations - Pro-

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mote early success and carryover, identify and use powerful motivators, and consider how to motivate students to work hard, to learn new skills, and to better tolerate situations that previously precipitated frustration.

- **Allocate resources thoughtfully** - Intervention and teaching-team members need solid training in order to implement teaching procedures and services. Regularly scheduled team meetings promote coordination, particularly when multiple disciplines are involved.
- **Engage parents** - Not only is it important to continually seek input from parents about treatment priorities and goal selection, but parents also benefit from the training, collaboration, and information that will enable them to embrace their role as a co-pilot in their child's intervention. This support should include siblings, grandparents, and other significant individuals if parents consent to their involvement. Engagement should occur throughout the educational journey and be adjusted to face the unique needs and challenges at each point in time.
- **Take data collection seriously** - Ongoing data collection enables one to objectively assess progress, make timely adjustments, and remain accountable to those we serve. No provider should get a "pass" on data collection.
- **Start early and get it right from the start!** - We know that early intervention can make an

High quality education for students with autism includes the following elements:

- **Be truly individualized** - plan should focus on needs, as determined through ongoing, valid assessment.
- **Be comprehensive** - high quality education targets the full array of skills that will promote success at home, school, and community, using a wide range of techniques based on science.
- **Keep the future in mind** - skills needed to be successful, independent and marketable in the next setting, must be identified and addressed.
- **Use well conceptualized behavior management strategies** – take into account the underlying function of behavior, include carefully selected antecedent- and consequence-based supports, and build skills to help students better promote their day-to-day independence and opportunities.
- **Consider and offer inclusion opportunities** - inclusion is not simply exposure; rather, inclusion is a systematic, individualized process, with proper supports, ongoing monitoring of data, and a goal of challenging the student with autism while not overwhelming them.
- **Implement instruction, including modifications and accommodations** - promote early success, and consider how to motivate students to work hard, to learn new skills, and to better tolerate situations that previously precipitated frustration.
- **Allocate resources** - team members need training in order to implement teaching procedures and services. Regularly scheduled team meetings promote coordination.
- **Engage parents** - seek input from parents about treatment priorities and goals, but also train, collaborate, and inform parents. Include siblings, grandparents, and other significant individuals for whom consent is given.
- **Take data collection seriously** - ongoing data collection enables one to objectively assess progress, make timely adjustments, and remain accountable to those we serve. No provider should "pass" on data collection.
- **Start early and get it right from the start!** - don't squander precious time on interventions that are not time-tested and research-based.

Children with autism are not guinea pigs

Science matters.
Choose wisely.

Learn more at
www.asatonline.org



ASAT Real Science, Real Hope

ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

The Pitfalls of Testimonials

Daniel W. Mruzek, PhD, BCBA-D

When searching for a great restaurant or choosing a movie to go see, we often consider advice from friends. Why not? Their “testimonies” give us ideas. Of course, they’re not always right, but their testimonials serve as shortcuts in our decision making when the stakes are low.

Testimonials are usually made by happy consumers and presented by marketers of autism treatments. We’ve all seen them on websites marketing pills, exercises, devices, interventions and therapies to unwary consumers. Marketers know that the testimonials of some people, including attractive people, familiar celebrities, and people who may remind the potential consumer of him- or herself, may be effective.

Can we use testimonial evidence in selecting autism treatments? When confronted with testimonials about possible interventions it is recommended that families be very cautious, particularly when the testimonials are the only source of support for the intervention. Marketers can find a few individuals who provide testimony that their product is effective, even if the product is ineffective. As consumers, our opinions about the quality of a product - including its effectiveness - are colored by our experiences, what we have been told by others, and our expectations. Human behavior - including the behavior of individuals with autism - is variable (i.e., changes across time), a treatment benefit may appear to exist even when it does not exist.

Imagine that a marketer sold a “special” trampoline to 100 parents with the guarantee that daily use of the trampoline by their child would “open learning channels” and “promote language acquisition.” It is reasonable to expect that at least a small number of them - perhaps five or 10 - may report that the product “seems to help,” even if the trampoline is not at all effective as an intervention. This small subgroup of consumers becomes their source for new testimonials!

And how about all of the parents who purchased the trampoline and subsequently recognized that it did not work? You can be assured that their opinions will not grace the marketer’s website, social media or glossy print advertisement.

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Question	Notes
1 "What is the rationale or theory underlying this intervention?"	The marketer's description of the rationale should sound reasonable. Be aware of scientific-sounding explanations that sound impressive but, upon consideration, are not plausible, logical or realistic.
2 "Do any scientific papers (e.g., peer-reviewed journal articles) indicate that the proposed treatment is effective?"	Watch out for references to testimonials, opinion pieces, case studies and "articles" that have been posted without scientific peer review. They can provide an illusion of legitimacy and effectiveness when, in fact, no scientific evidence may exist.
3 "What should the benefits of the intervention look like, and how will we monitor/measure these?"	The practitioner or marketer should be able to offer specific and observable potential benefits and an objective method of measuring gains for your family member.
4 "Do you have data or stats from your practice that suggests that this treatment works?"	If the practitioner cannot point to scientific studies supporting their proposed intervention, ask to see treatment data for other individuals with whom they have worked in the past. The practitioner should not provide you with the name or other identifiers of the individual they treated - just a good description of what they did and data that demonstrate functional improvement for the individual.
5 "What are the possible side effects, and how will we monitor/measure these?"	Many interventions have potential unintended consequences that should be considered beforehand and, if concerning, monitored for during implementation.
6 "How much time does it take, and when will it be done?"	Even a brief intervention (such as a 10-minute exercise during the school day) adds up to substantial time lost for other, possibly important, activities (e.g., skill building); therefore, one question to consider is what will <i>not</i> be done due to implementation of the proposed intervention?
7 "How will we monitor treatment data for my family member?"	Watch for the use of objective (i.e., measurable) data to assess for possible treatment effectiveness. And, of course, objective data are of no use if the intervention team is not regularly reviewing these data and incorporating these data into treatment decisions. Will the data "pile up" in a folder or drawer, or will the intervention team maintain a schedule of ongoing review?
8 "How difficult is it to implement this treatment correctly?"	Beware of proposed interventions that require that they be implemented "just right" in order to be helpful. This quality can be an excuse that marketers use when unwary consumers question a lack of progress. Usually, an effective intervention is helpful even if not implemented with perfect fidelity.

Questions to Ask Marketers of Autism Interventions

Daniel W. Mruzek, PhD, BCBA-D

Families with a member with autism know that there is a vast selection of potential treatment options. Some of these treatments are purported to address one or more of the core features of autism (e.g., a pill that supposedly improves spoken communication), while others are marketed as treatments for other difficulties commonly experienced by individuals with autism (e.g., exercises to reduce tantrums). Many of these interventions are expensive and time-consuming, and some are potentially dangerous (e.g., hyperbaric chamber). Like other “purchasing” decisions, families need to consider treatment options carefully.

How does one investigate these options? One way is to ask a trusted expert (e.g., a physician, psychologist, or behavior analyst). Another way is to reference science-based “quick reference” guides, such as ASAT’s web-based Summaries of Scientific Research on Interventions on Autism. A third way to investigate the soundness of a potential autism treatment is to ask the marketer or practitioner polite but direct questions about the treatment that they recommend. Below, we have eight questions that you may ask marketers of autism interventions that may be helpful as you make treatment decisions.

Family members might be a little apprehensive about asking marketers of purported autism interventions direct questions about the state-of-the-science of their interventions; however, a legitimate interventionist will appreciate good questions and the resultant opportunities to partner with the family in the development of effective treatments. This process of direct questioning is one way we can practice scientific skepticism – a quality of the scientific process that makes it such a powerful means of positive change. Also, this process increases the likelihood that hard-earned family income is spent wisely towards maximizing the independence of the member with autism.

Additional information on selecting treatments for your family member is found in an article entitled *The Road Less Traveled: Charting a Clear Course for Autism Treatment*, authored by David Celiberti and colleagues and found in this Autism Resource Guide.

Caveat Lector: Let the Reader Beware

David Celiberti, PhD, BCBA

The decisions of many consumers are influenced by what they read in the newspaper or on the Internet and hear about on television or on the radio. It is our belief that access to effective treatment for the autism community is enhanced with accurate representations of autism treatment in the media. Unfortunately, many media representations are fraught with inaccuracies. Additionally, effective treatments typically receive less press because their providers are often focusing on maximizing outcomes in an accountable manner rather than on soliciting media attention.



Many of you are familiar with the Latin phrase, “Caveat Emptor” which means that “the buyer alone is responsible for checking the quality and suitability of goods before a purchase is made.” With scores of “miracle cures” and “breakthroughs” for autism receiving widespread media attention well before they have been shown to be beneficial through credible, peer reviewed research, “Caveat Lector: Let the Reader Beware” seems to be a very suitable guiding principle across all media platforms (e.g., print, radio, television, Internet). In other words, the reader is put in the position of being responsible for evaluating the quality and suitability of information being presented to him or her.

As a consumer, you bear a responsibility to scrutinize sensational claims related to various autism treatments and to be knowledgeable enough to consider such stories through a skeptical lens. We wish you did not need to work so hard to differentiate good and bad information, but that is the sad reality of autism treatment today, with 500+ treatments being touted. With that in mind, when reading or hearing an autism treatment story in the media, please consider the following questions:

About the Intervention

- Does the article or story actually describe how the intervention helps individuals with autism? In what ways? Are those ways observable and measurable? substantial? meaningful?
- Does the article or story report the costs of the intervention? Are these costs reasonable

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both in monetary and human resources terms?

- Is there any report of harm imposed by this intervention? What are the risks? What are the side effects? Does the article or story appear balanced between these?

- Who can carry out this intervention? What kind of education, training and supervision do individuals need to have before implementing the intervention?

About the Experts

- Whom did the author interview for this story and what are his/her qualifications? Is this person presented as an expert?

- Is the interviewee making claims of efficacy/effectiveness that are supported by scientific data? What does he or she stand to gain by this story? *Who* may benefit financially from this particular media exposure? How would they benefit?

About the Underlying Scientific Support

- Did the article or story mention the existence of published research articles in peer-reviewed journals documenting the efficacy of the intervention method discussed? If not, could it mean that no such research exists?

- If so, did the author comment on whether these studies were well designed? Are they presented as an extension of existing work, or rather sensationalized as a breakthrough keeping in mind that often interventions are pitched as a “breakthrough,” when indeed they are not?

Some Final Questions to Consider

- Are other media outlets reporting this article (or a similar story)? Were they favorable or unfavorable? Did they consider data in their opinions?

- Has ASAT responded to this article? See www.asatonline.org/media-watch/

- Have they consulted with an unbiased and knowledgeable individual for his/her input about the intervention described (e.g., someone who is not personally benefitting from the story or someone with a strong grasp of research)?

Explaining My Decision to Use Science-Based Treatments for Autism (when friends and relatives insist I try something new)

David Celiberti, PhD, BCBA
Pamela F. Colosimo, PhD

When friends or acquaintances hear about our experiences with autism, quite often the first thing they ask is, “What is your opinion of vaccines?” Then, in many cases, that person asks if we have heard of or read anything about Jenny McCarthy and how she treated her son’s autism. The vaccine debate is an issue that lingers on, despite the retraction of Andrew Wakefield’s article by the *Lancet* (a very rare occurrence by this highly reputable journal). Sadly, the vaccine debate has distracted the autism community from important topics such as how best to help children already diagnosed with autism realize their fullest potential.

As citizens, we respect any individual’s right to his or her own opinion, and certainly for parents of children with autism to make decisions for their child regarding treatment. The late Senator Patrick Moynihan eloquently said, “Everyone is entitled to their own opinions, but not their own facts.” As scientists, we believe that objective data and evidence should guide treatment options

for all diseases and disorders, and autism is no exception. It is simply a matter of fact that theories, hypotheses and individual experiences do not provide adequate information to guide treatment decisions.

Sadly, the controversies surrounding vaccines have detracted attention from the most important of conversations: How do we help effectively children who are *already* diag-

nosed with autism? Although applied behavior analysis is the treatment for autism with the most empirical support, we are rarely ever asked our opinion of this therapy, or if it is effective.

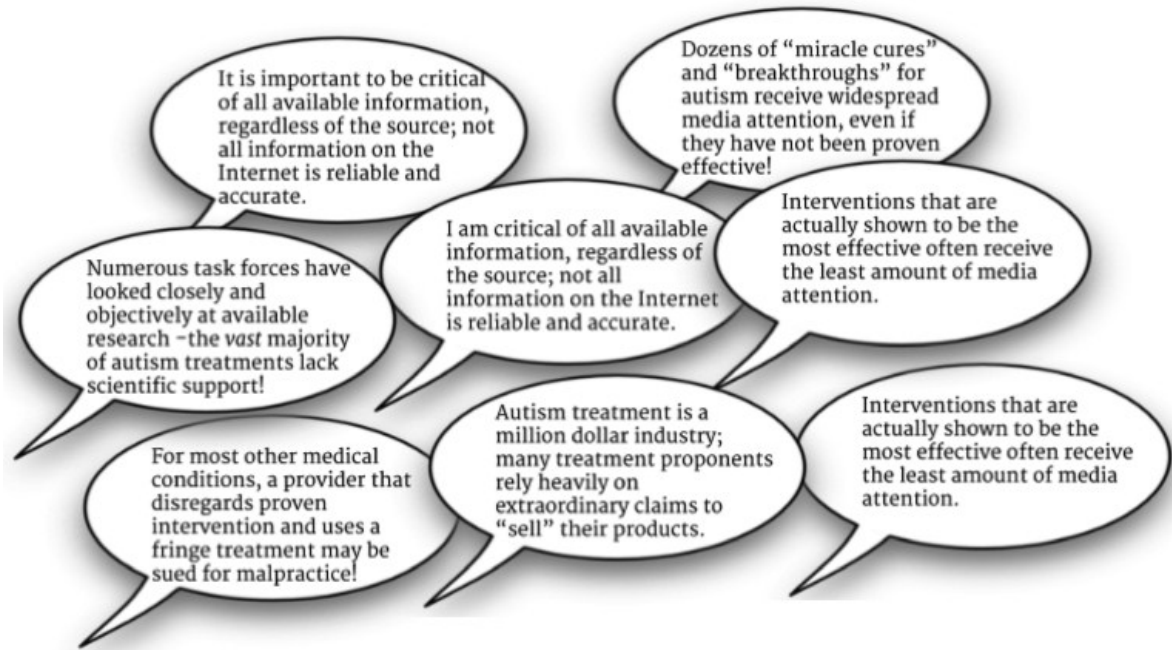
Every few months or so, some “new” treatment (or “repackaging” of a known treat-

ment) will gain the attention of consumers. In an ideal world, all treatment providers would make a commitment to science and evidence-based practices, and the



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would make a commitment to responsible journalism. Until these ideals become reality, those who do understand science-based treatments should do what they can to inform and educate others about the benefits of scientifically validated treatment, and the use of data to guide decision-making when assessing autism treatments.

Given the large numbers of television programs, newspaper articles, and websites putting forth "miracle cures" and "breakthroughs," it is not surprising that parents frequently receive advice and suggestions from extended family members, neighbors, and co-workers, particularly after a news item is broadcast, printed, or otherwise disseminated. Many of these individuals have the best intentions and are eager to share what they believe is "cutting edge" information about autism. In other cases, the advice is sometimes provided in a manner that comes across as critical of what you are

choosing to do or not do for your child (i.e., it may be implied that you are not doing enough as a parent to help your child with autism).

If the information is offered by a more casual acquaintance, it may be best to simply thank him or her for their interest and concern and move on; however, such a strategy may not fare as well with individuals with whom you have a closer relationship. In these cases, you might consider sharing the following:

- There are dozens of "miracle cures" and "breakthroughs" (i.e., pseudoscience) for autism that manage to receive widespread media attention, even if they have not been proven effective;
- It is important to be critical of all available information, regardless of the source and

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to recognize that not all information on the internet is reliable and accurate;

- There is a large body of scientific research published in peer-reviewed journals that supports the choices that you have made;
- Numerous task forces (some are listed at the end) have looked closely and objectively at the available research and have determined that the *vast* majority of autism treatments lack *any* scientific support;
- Autism treatment is a multi-million dollar industry and many treatment proponents rely heavily on sensationalism and extraordinary claims to “sell” their products;
- Interventions that are actually shown to be the most effective often receive the least amount of media attention; and
- For most other medical conditions, a provider that disregards proven intervention and uses a fringe treatment may actually be sued for malpractice (you may even consider drawing an analogy to a medical condition of particular interest to the person providing the advice).

Of course, you may also consider addressing this matter proactively. This would involve clarifying your choices and commitment to science-based treatment to more significant family members and friends on your terms and at your convenience. It may be helpful to view this tactic as a series of tiny conversations. You may even consider sharing links to websites such as www.asatonline.org, which will help your family members and

friends separate the wheat from the chaff. This response would not be replete without drawing your attention to a few sections of ASAT’s website that bear relevance to this discussion.

- Summaries of Scientific Research on Interventions on Autism
www.asatonline.org/for-parents/learn-more-about-specific-treatments/
- What is Evidence-Based Practice and Why Should We Care? www.asatonline.org/research-treatment/making-sense-of-autism-treatments-weighing-the-evidence/what-is-evidence-based-practice-and-why-should-we-care/
- Recommendations of Expert Panels and Government Task Forces
www.asatonline.org/?page_id=197

As you know, ASAT’s newsletter, *Science in Autism Treatment*, is a free publication, so encourage your friends and family to sign up. It is our hope that this may help your friends and family better understand the role that science should play in the treatment of autism, the importance of parents becoming savvy consumers, the need for objective data to drive decision making, and how to identify pseudoscience.

What Do I Look For in a Behavioral Service Provider?

Effectiveness of the interventions they use. Formal credentialing of professional behavior analysts (i.e., registration, certification, or licensure) can provide safeguards for consumers, including means of screening potential providers and some recourse if incompetent or unethical practices are encountered. At present, however, procedures for credentialing professional behavior analysts are in place in only a few states. Consumers are encouraged to review the [Revised Guidelines for Consumers of Applied Behavior Analysis Services to Individuals with Autism and Related Disorders](#). This helpful tool was developed by the Autism Special Interest Group of the Association for Behavior Analysis.

I. The qualifications embodied in the standards for certification as a behavior analyst in the State of Florida, Department of Children and Families, which can be summarized as follows:

Formal training

- Master's or doctorate in behavior analysis, or in psychology, special education, or another human service discipline with an emphasis in behavior analysis
- Coursework in principles of learning, principles of behavior, or basic behavior analysis; experimental analysis of behavior; behavioral assessment or methods of direct observation of behavior; applied behavior analysis; single-subject research designs; legal and ethical issues
- Supervised practicum, internship, or employment experiences in applied behavior analysis

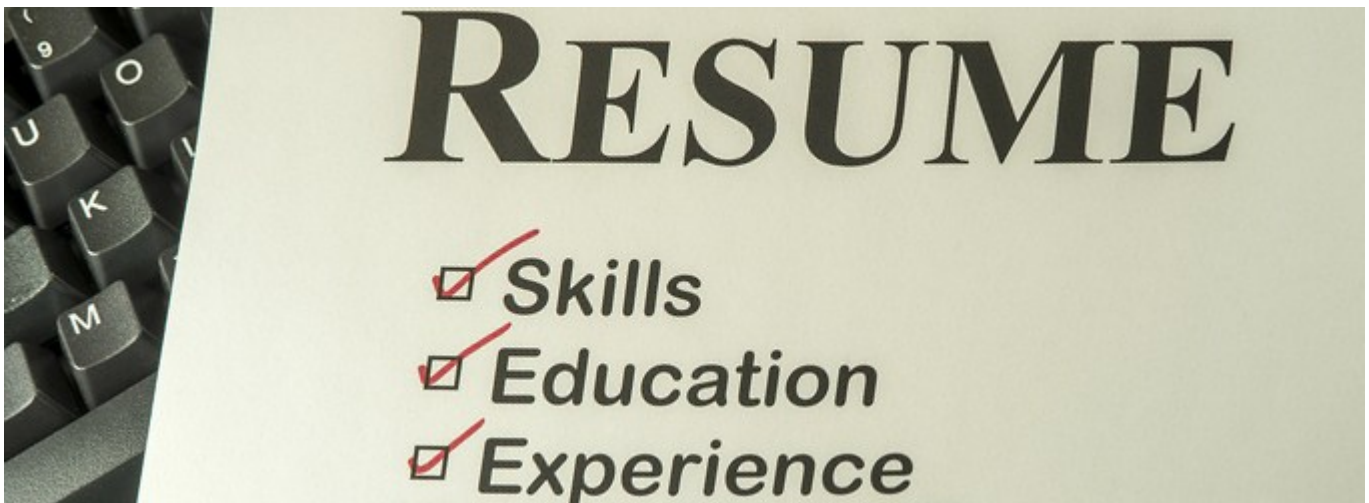
Competencies

- Ethical considerations
- Definition and characteristics of applied behavior analysis
- Basic principles of behavior
- Behavioral assessment
- Descriptive analysis
- Demonstrating functional relations

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- Measurement of behavior
- Data display and interpretation
- Selection of target behaviors and goals
- Behavior change procedures
- Generalization and maintenance of behavior change
- Managing emergencies
- Transfer of technology
- Support for behavior analysis services



For details, see “Identifying qualified professionals in behavior analysis” by G.L. Shook & J.E. Favell in *Behavioral Intervention for Young Children with Autism*, edited by C. Maurice, G. Green, & S.C. Luce; Austin, TX: PRO-ED, 1996; and “Essential content for training behavior analysis practitioners,” by G. L. Shook, F. Hartsfield, & M. Hemingway, *The Behavior Analyst*, 1996, Vol. 18, pp. 83-91.

II. Additional training and experience in directing and supervising ABA programs for individuals with autism:

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- Formal training and/or self-study to develop knowledge of the best available scientific evidence about the characteristics of autism and related disorders, and implications of those characteristics for designing and implementing educational and treatment programs, including their impact on family and community life.

- Formal training and/or self-study to develop knowledge of at least one curriculum consisting of:

1. Scope and sequence of skills based on normal developmental milestones, broken down into component skills based on research on teaching individuals with autism and related disorders;

2. Prototype programs for teaching each skill in the curriculum, using behavioral methods;

3. Data recording and tracking systems; and

4. Accompanying materials.

5. At least one full calendar year (full time equivalent or 1000 clock hours [$@ 25 \text{ hrs/wk}$ for 40 weeks]) of hands-on training in providing ABA services directly to children and/or adults with autism under the supervision of a behavior analyst with a master's or doctorate and at least 5 years' experience in ABA programming for individuals with autism. The training experience should include at a minimum:

6. Provision of ABA programming to at least 5 individuals with autism.

7. Designing and implementing individualized programs to build skills in each of the following areas: "learning to learn" (e.g., observing, listening, following instructions, imitating); communication (vocal and nonvocal); social interaction; self-care; academics; school readiness; self-preservation; motor; play and leisure; community living; work.

8. Using both discrete-trial and incidental or "naturalistic" teaching methods to promote skill acquisition and generalization.

9. Incorporating the following into skill-building programs: prompting; error correction; discrimination training; reinforcement strategies; strategies for enhancing generalization.

10. Modifying instructional programs based on frequent, systematic evaluation of direct observational data.

11. Designing and implementing programs to reduce stereotypic, disruptive, and destructive behavior based on systematic analysis of the variables that cause and maintain the be-

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havior.

12. Incorporating differential reinforcement of appropriate alternative responses into behavior reduction programs, based on the best available research evidence.

13. Modifying behavior reduction programs based on frequent, systematic evaluation of direct observational data.

14. Provision of training in ABA methods and other support services to the families of at least 5 individuals with autism.

15. Provision of training and supervision (at least 1 hour of supervision per 10 hours of client contact for at least one-half of the training period) to at least 5 professionals, paraprofessionals, or college students providing ABA services to individuals with autism.

The Autism SIG urges consumers to ask prospective directors or supervisors of ABA services to provide documentation of their qualifications in the form of: membership in the Association for Behavior Analysis; degrees; letters of reference from employment supervisors and/or families for whom they have directed ABA programming for similar individuals with autism (with appropriate safeguards for privacy and confidentiality); any registration, certificate, or license in Applied Behavior Analysis per se (i.e., not psychology, special education, education, or another discipline with no emphasis in behavior analysis); results of any competency exams they may have taken in Applied Behavior Analysis; participation in professional meetings and conferences in behavior analysis; publications of behavior analytic research in professional journals. A few workshops, courses, or brief hands-on experiences do not qualify one to practice Applied Behavior Analysis effectively and ethically.



ASAT Real Science, Real Hope
ASSOCIATION FOR SCIENCE IN AUTISM TREATMENT

ASAT publishes Science in Autism Treatment (SIAT).

The free quarterly e-newsletter featuring:

- Invited articles by leading advocates of science-based treatment
- Clinical Corner responses to frequently asked questions about autism treatment
- Consumer Corner descriptions of resources that can guide and inform treatment decisions
- Detailed summaries of specific treatments for autism
- Book reviews
- Highlights of our Media Watch efforts with discussion of accurate and inaccurate portrayals of autism and its treatment by the media
- Reviews of published research to help consumers and professionals understand and access the science
- Summaries of policy statements related to autism treatment
- Interviews with those advancing science-based treatment and confronting pseudoscience
- Announcements about upcoming conferences of interest
- Guidelines to help consumers access effective treatments
- Links to helpful resources and articles already offered on www.asatonline.org

Our mission is to educate parents, professionals, and consumers by disseminating accurate, scientifically-sound information about autism and its treatment and by combating inaccurate or unsubstantiated information. In doing so, we promote the use of effective, science-based treatments for all people with autism, regardless of age, severity of condition, income or place of residence.

ASAT is a not-for-profit organization dedicated to disseminating accurate, scientifically-valid information about autism education and treatment.

For more information, please visit our website at



www.facebook.com/ASATonline



www.twitter.com/ASATonline

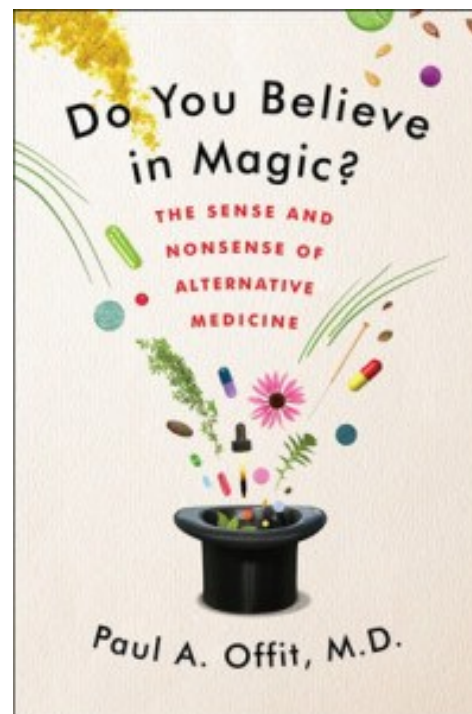
Reviews

Review of:

Offit, P. (2013). *Do you believe in magic? The sense and nonsense of alternative medicine*. New York, NY: Harper Collins Publishers

**Lori Ernsperger, PhD, BCBA-D
President, Autism and Behavioral Consulting**

This quote, “What people believe, prevails over truth,” written over 2,000 years ago by Sophocles, an ancient Greek writer, is exemplified throughout the book, *Do You Believe in Magic?* by Dr. Paul Offit. Dr. Offit is the Chief of the Division of Infectious Diseases and Director of the Vaccine Education Center at the Children’s Hospital in Philadelphia. You may be familiar with Dr. Offit’s earlier works, which include *Autism’s False Prophets* (2008) and *Deadly Choices: How the Anti-Vaccine Movement Threatens Us All* (2011). Dr. Offit has never shied away from controversy, and in this book he challenges his readers to examine the field of alternative medicine through the lens of scientific methods and peer-reviewed research. Dr. Offit fearlessly attempts to uncover the truth behind alternative treatments such as acupuncture, dietary supplements, chiropractic interventions, and various other unregulated cures for cancer, Lyme disease, heart disease, and autism. This important, and well-written book makes a case for disseminating the truth and educating the public while attempting the difficult task of combating what people choose to believe.



Dr. Offit provides readers with a detailed historical account of the Food and Drug Administration (FDA) and the pertinent federal regulations for consumer protection which began to slowly evolve in the early 1900s. At the turn of the last century, there were no set regulations governing food preparation, food handling, or the accuracy of statements made by the food industry regarding product safety and nutritional ingredients. Several laws, passed between 1906 and the 1960s, established some basic food industry standards, and stipulated that pharmaceutical companies had to actually prove that drugs did not cause serious harm, such as was the case with Thalidomide in the late 1950s and 1960s. By 1975, the FDA began regulating the pharmaceutical industry, but vitamins, supplements, and other herbal remedies were not under the FDA umbrella and thus, could continue to make false claims of effectiveness without publicly disclosing their ingredients or side effects.

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The Proxmire Amendment of 1975 was written specifically to prohibit the FDA from establishing standards to limit the potency of vitamins and minerals in food supplements or regulating them as drugs based solely on their potency. The passing of the Proxmire Amendment gave vitamin and supplement manufacturers carte blanche to self-regulate and create what has become a \$34 billion industry over the last thirty years. Even the most recent federal law, the Dietary Supplement Health and Education Act (DSHEA), passed in 1994, has done little to change this, as all vitamins, supplements and other dietary ingredients continue to go unregulated and manufacturers are still not required to label the ingredients or provide evidence of effectiveness. According to the New York Times, the DSHEA of 1994 should be referred to as the “Snake Oil Protection Act” (p. 260 Kindle Edition).

FACT: As of 2013, in the United States, manufacturers can produce vitamins, herbal remedies, or other products and label them “dietary supplements,” which then excuses them from any testing, data, scientific evidence, clinical trials or FDA approval for human consumption.

Dr. Paul Offit details several important reasons why alternative medicine is not regulated and why Americans believe in its efficacy and are willing to pay for these expensive treatments. First, the role of celebrity endorsements has long been a tradition in supporting alternative medicines and scam treatments. Steve McQueen was an early proponent of alternative treatments for cancer. He traveled to Mexico in his final days to receive laetrile, which at the time, was being touted as an alternative cancer cure made from crushed apricot pits. Unfortunately, although his choice in treatment did not cure his cancer, it propelled laetrile into the mainstream medical community, where vulnerable cancer patients requested this treatment from traditional doctors. Dozens of other celebrities have endorsed alternative cures and treatments including Larry King, Mike Wallace, Whoopi Goldberg, Mel Gibson, Regis Philbin, Steve Jobs, and the mega-alternative celebrity, Suzanne Summers. Ms. Summers has created a multi-million dollar industry built on attempting to turn back the hands of time with anti-aging compounds, creams, and bioidentical hormone replacement therapy, despite a lack of peer-reviewed research proving these claims. Such celebrity endorsements have propelled the popularity of alternative medicine without any regulation or scientific proof of efficacy.

FACT: 51,000 supplements have been manufactured in the US over the last 10 years and yet only 0.3% have been tested and documented safe for human consumption.

In addition to celebrity endorsements, the vitamin and dietary supplement industry has political clout. Politicians from Bob Dole, Orin Hatch, Richard Blumenthal, Joe Barton, and most recently, Dan Burton, have all supported alternative medicines and have blocked any legislation from restricting or regulating this industry. Each of these political figures has

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taken great steps to ensure less regulation for alternative treatments without any regard to the scientific data or human sacrifice. For example, Joe Barton a politician from Texas, supported antineoplaston (urine) treatment for cancer and repeatedly stated, “FDA, go away.” This is in the face of every clinical trial proving its lack of efficacy and denouncements from the American Cancer Society. Dr. Offit details the motivations of politicians which are often financial or based on personal beliefs and anecdotal cases from their constituents.

Unfortunately scam treatments and frauds have targeted one of our most vulnerable populations, children with autism spectrum disorders (ASD) and their families. The clash of ASD treatment and alternative medicine is a perfect storm rife with celebrity endorsements and political support. Dr. Offit spends several chapters describing the various fad treatments which have emerged in recent years claiming to “cure” autism, including mega doses of vitamins, chelation, stem cells, chiropractic manipulations, digestive enzymes, secretin, hyperbaric oxygen therapy, and even coffee enemas. As Dr. Offit explains, “parents of children with autism will do anything to help their children” (p. 392 Kindle Version), and as a result, they subscribe to the unsubstantiated claims of celebrities who have led the charge towards alternative therapies and expensive interventions. A parent of a child with ASD who was interviewed by Dr. Offit shared, “I don’t blame the parents for being susceptible to this. The culpability lies with the quacks who are preying on desperate families” (p. 400 Kindle Version). Dr. Offit offers credible scientific evidence to refute these treatments, but this is an uphill battle, as detailed in his chapter entitled, “Charismatic Healers are Hard to Resist,” which describes the fraudulent work of Dr. Rashid Buttar (www.drbuttar.com) and his “cure” for autism.

Scientific evidence, data, conventional medicine, and clinical trials sound old and boring. Dr. Offit points out that most traditional doctors often lack the magnetic personality, sales pitch, and rapid fire charm which are sold in a bottle of vitamins or a cure for autism using “natural” remedies and creams. The charisma of Dr. Oz and others in the mainstream media who report that acupuncture is 3,000 years old and based on wise Chinese tradition is filled with intrigue and hope. Dietary supplements and alternative treatments offer a cure for some of the most awful diseases and disorders that afflict millions of children and adults. Dr. Offit explains how the marketing of alternative medicine is based on fraudulent snake oil salesmen who are not selling the truth, but rather, what people want to believe.

FACT: *Natural does not necessarily mean healthy or safe.*

There is a myth that if something is grown from the Earth it is healthy. Conduct a quick Internet search of “Earth, Nature, Green and Vitamins” and you will find dozens of highly lucrative manufactures who propel this myth. Unfortunately, it is a fact that there are hun-

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dreds of plants which grow from the Earth but have poisonous chemicals and should not be consumed by humans in dietary supplements.

Whether you are an advocate for scientific inquiry and empirical research on alternative medicine (e.g., BCBA) or simply want the facts on taking a daily multivitamin, this book will meet and exceed your expectations. Dr. Offit provides a fascinating and accurate account of the state of alternative medicine in the United States. He compels us to examine the statement posed by Sophocles: *“what people believe, prevails over truth.”* As scientists dedicated to promoting the truth about effective treatments for individuals with ASD, we must continue to assist and educate families in their beliefs about traditional and conventional scientific methods. We, behavioral scientists, along with other professionals, must sell our evidence-based truth as strongly and charismatically as the charlatans who are selling a cure in a bottle. Dr. Offit reminds us not to shy away from confronting those who wish to hide the truth and asks, *Do You Believe in Magic?*

References

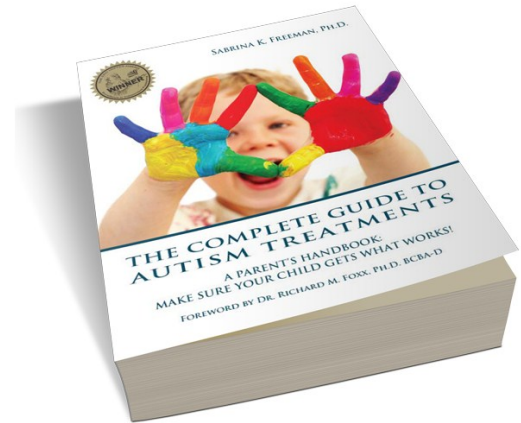
- Offit, P. A. (2008). *Autism false prophets: Bad science, risky medicine, and the search for a cure*. West Sussex, England: Columbia University Press.
- Offit, P. A. (2011). *Deadly choices: How the anti-vaccine movement threatens us all*. New York: Basic Books.

Review of:

Freeman, S. K. (2011). *The complete guide to autism treatments. A parent's handbook: Make sure your child gets what works!* (2nd edition) Bellingham, WA: SKF Books, Inc.

**David Celiberti, PhD, BCBA-D
Carolyn J. Sniezyk, MS, BCBA**

Just when we think we have seen everything, we are reminded that with autism treatments anything and everything is possible, particularly given that many individuals have recognized that autism treatment can be a very lucrative business. The array of treatments for autism is indeed quite diverse and include treatments that are downright dangerous and taken together can be absolutely overwhelming. Thankfully, there is a book available to help parents and other consumers with this laborious task while also helping them to develop the skills needed to differentiate science from pseudoscience and viable options from nonsense.



The Complete Guide to Autism Treatments Second Edition is comprehensive, thoroughly researched, and well organized. Throughout, Dr. Freeman communicates a critically important message: individuals with autism deserve access to science-based treatment - their time, their potential, and the overall resources of their families should not be wasted. As will be detailed below, Dr. Freeman shares her perspectives as a mother, which further contributes to the authenticity of this book, and may appeal to parents who may be more receptive to the cautionary words of one who walks in their shoes.

The second edition of *The Complete Guide to Autism Treatments* begins with a forward by Dr. Richard M. Foxx which details the importance and quality of the book in addition to a well written summary of the content. Following the forward, the reader will find that the book is divided into two primary sections. Section I is organized around topics related to the various treatments for autism. Section II highlights basic concepts about science, hypothesis testing, and research methodology. Each of these will be discussed below.

- Section I begins with a review of behavior-analytic treatments for autism across home and school settings, as well as within the area of early intervention. The various offshoots of applied behavior analysis are also summarized and evaluated (e.g., intensive behavioral treatments, pivotal response training, positive behavior support, verbal behavior therapy,

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and fluency training). Then there is a fairly comprehensive subsection related to the myriad of non-behavioral treatments, including those that occur in school, as well as those that are child-initiated or parent-facilitated. These subsections are followed by biomedical therapies, speech and language therapies, and ultimately, a final section for miscellaneous therapies not better categorized in the above subsections. Each of these subsections is divided, and in some cases divided further, in an effort to capture the more frequently-touted treatments for autism. Each of these treatment subsections is organized around responses to a series of 8-9 questions. These questions are applied to each treatment discussed. (see table at end of the review).

- Section II, titled "How do we know what works and what doesn't?" focuses on the scientific method, hypothesis testing, and research methodology. At times, the content may seem somewhat dense, but that speaks more to the complex nature of scientific inquiry than to Dr. Freeman's writing style. These more technical sections are preceded by a number of caveats empowering parents to question the "experts" whom they will undoubtedly encounter over the course of their child's treatment. There is considerable attention paid to the components of research, data interpretation, and analysis of a study, as well as descriptions of many all-too-common red flags in autism treatment.

- Section II also includes an Afterword which provides information regarding how the literature review was conducted for the second edition, some conclusions regarding the more recent research that was used to update this publication, and a review of new therapies that have gained popularity since the first edition. Section II ends with 54 pages of references!

This book has many notable strengths.

1. The format of nine recurring questions within Section I provides a predictable framework for the reader. In fact, Dr. Freeman's careful analysis of the state of the research underlying specific Applied Behavior Analysis (ABA) treatments is offered in the same spirit and with the same diligence as the non-behavior analytic treatments.

2. Proponents of the various treatments would benefit from careful consideration of the suggestions offered in the "What kind of study would I like researchers to do?" section. Far too often, a single study is put forth as validation of an entire treatment and all of its theoretical and conceptual underpinnings. The reader will find that Dr. Freeman has individualized her recommendations based on each treatment's existing research history. Execution of these research agendas may enable a number of treatments to live up to their promises.

3. Perhaps of greatest significance is that the author is writing from the dual perspectives of professional and parent. When speaking as a parent, her commitment to science is unwa-

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vering, and appropriately so; she is unapologetic in sharing her perspectives as an informed mother. This is greatly needed at a time when many individuals fear being perceived as close-minded or unwilling to recognize the contributions of other disciplines. Her professional perspective only adds further credence to her stance regarding treatment options. There are wonderful insights throughout the book which will make this resource useful to those who will tend to read this book a few parts at a time. For instance, there is a very interesting discussion at the beginning of the book about participation in research with the caveat that precious time and resources should never be wasted on low-quality research, for not all research is created equally.

In summary, we believe *The Complete Guide to Autism Treatments* is a much needed contribution to the field of autism. The diligence and comprehensiveness of the various treatment reviews make this book an important “go-to” resource for parents and professionals alike. Undoubtedly this is a resource that the reader can expect to pick up time and time again.

Questions applied to the treatments highlighted in Dr. Freeman’s book:

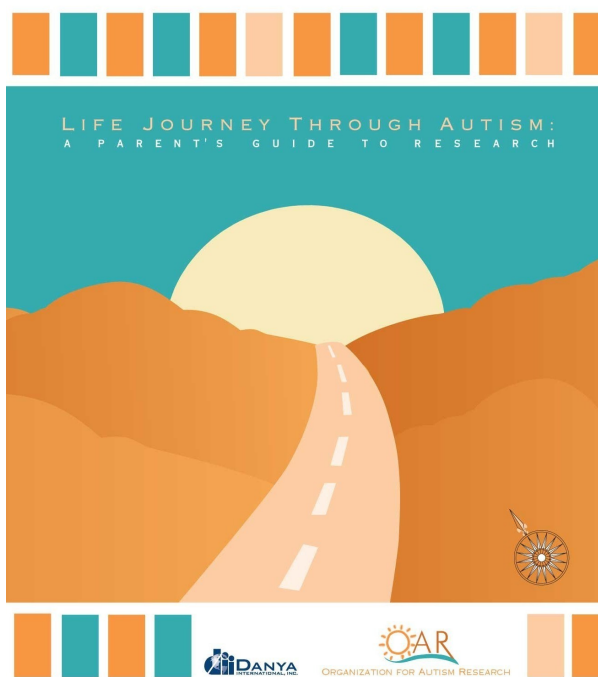
<p>“What is _____?”</p>	<p>Dr. Freeman defines the treatment, highlights its purpose or intent with respect to autism, and describes its rationale and theoretical underpinnings. The proponent’s more significant hypotheses about autism’s etiology and treatment are often described as well.</p>
<p>“What evidence do the practitioners have that this really works?”</p>	<p>Dr. Freeman summarizes and evaluates peer-reviewed research and other possible sources of support (e.g., anecdotal evidence). She reports the results of database searches and is often quite explicit about numbers of articles that fall into categories (e.g., non-published studies, pamphlets, published in peer-reviewed journals, published in non peer-reviewed journals).</p>
<p>“What does this therapy actually look like?”</p>	<p>Dr. Freeman describes, often in great detail, the actual procedures associated with the treatment. This information is essential, as many consumers know little about the therapies to which they are subjecting their children. These descriptions are written in an objective, non-partial manner which, when read in isolation, would not necessarily reveal the author’s stance on a particular treatment. Information about side effects and/or adverse effects is provided when warranted.</p>
<p>“Would I try it on my child?”</p>	<p>In contrast to the objective and factual tone of her responses to the questions above, here Dr. Freeman offers a more personal take on the treatment: a take that is honest and at times, blunt. Clearly, every child with autism is different, and thus, treatment decisions need to be made in consideration of those differences. Even if readers disagree with Dr. Freeman’s position, they will appreciate the candor and thoughtfulness of her position as a fellow parent.</p>

Review of:

Life journey through autism: A parent's guide to research. Arlington, VA: Organization for Autism Research, Inc.

Stacey Sipe, MEd
Alice Bravo, MEd

Reading through published research can often be a challenging and intimidating experience for many professionals. It can be even more overwhelming for parents of children with autism, who are tasked with digesting the technical aspects of the research literature; discriminating rigorous, well-designed research from poorly executed research; and making sense of the treatment implications of published findings.



A Parent's Guide to Research represents the collaborative efforts of the Organization for Autism Research (OAR) and Danya International, Inc. This resource was published in 2003, but continues to be useful to parents who are just beginning to consume autism research and to those wishing to delve deeper. The guide is targeted towards a parent audience; however, we find it useful for teachers and other service providers who are learning to navigate autism research as well. The result is a well-written and comprehensive resource, presented in an organized and comprehensible format.

A Parent's Guide to Research begins with an introduction detailing how to use the guide and highlighting key sections. Descriptions of these sections follow:

- How to be a savvy consumer of sources of autism information offers specific strategies for accessing published research. Tips for effective Internet searches of research articles and for contacting individual researchers are provided.
- Understanding the science model explains the difference between "basic" and "applied" research (basic research is conducted to advance scientific theories, whereas applied research tackles real-world problems). The five basic types of research studies are outlined:

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single-case, correlational, longitudinal, experimental, and clinical trial studies. A summary of the advantages and disadvantages of each is presented.

- A uniform framework for evaluating research describes the standard format by which a professional research article is reported, and walks readers through the content and purpose of each section (Abstract, Background/Introduction, Methodology, Results, Discussion, and References). Questions to consider when looking over each section of a research article are provided, such as, “What are the inclusion and exclusion criteria for subject selection?” and, “Do the instruments [used to collect data] measure what they are supposed to measure?” A general warning is provided to remain skeptical when evaluating research, and to look out for potential researcher conflict of interest.
- The current state of autism research describes the array of published and ongoing studies and warns readers to be wary of claims for “miracle” cures.
- Directions for future research offers parents insight into the types of questions that warrant further scientific inquiry. Broadly, these future research topics include causes of autism, early diagnosis, early intervention, educating children with autism, social and economic support systems for people with autism, jobs for people with autism, and individual quality of life assessment.
- The Glossary provides definitions of terms that readers will encounter when looking through research articles. Such terms can be quite intimidating to those not familiar with the language of research.
- Several Appendices are presented, including a description of the various theoretical perspectives on autism, information about participating in research, and sample research articles with embedded comments that label the various sections of a study. Note taking worksheets are available as tools for seeking out essential information while reading research articles, and include both a basic and more detailed template.

A Parent’s Guide to Research arms parents with the skills to identify and understand sound research studies surrounding autism treatment. These are important skills to develop when considering the dozens of available treatments that lack scientific support. A Parent’s Guide to Research positions parents to make sound choices in helping their children realize their fullest potential. An educated consumer base will undoubtedly support the advancement of both science and practice. A copy of A Parent’s Guide to Research can be [downloaded free](#).

Review of: Autism: Start Here. What Families Need to Know

Elizabeth Callahan, MA, BCaBA
David Celiberti, PhD, BCBA

In response to the countless families who have wondered if their child had autism and have been overwhelmed with worry and the sea of information available today in print and on the Internet, Autism New Jersey updated its 2012 primer for families. Written in an easy-to-understand format, this publication provides accurate and comprehensive information on what families need to know: autism, effective treatment, service providers, navigating state services, and more.

Autism: Start Here What Families Need to Know, provides a wealth of easy to navigate and accessible information to assist parents in key sections. Descriptions of these sections to follow:

What is autism and how is it diagnosed? This section defines what an autism spectrum disorder is, discusses red flags in typical development, and provides excellent tables and examples of what those “red flag” concerns typically look like with respect to key areas of development such as social interaction, communication, and behavior. Additionally, in this section an overview of the diagnostic evaluation is given. Finally, it addresses the limitations of the evaluation and also how common a diagnosis is.

Who’s who in autism services? This table provides an overview of 11 professionals a parent of a child with autism is likely to encounter and a description of the role that this professional would play. These include, a Board Certified Behavior Analyst (BCBA), Case Manager, Developmental Pediatrician, Director/Coordinator of Special Services, Neurologist, Occupational Therapist (OT), Pediatrician, Physical Therapist (PT), Psychiatrist, and Psychologist, and the Speech Language Pathologist. Links to websites to learn more about particular disciplines are also provided.

Introduction to state and local services. Describes how these services are administered in

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three categories, Early Intervention (EI) (birth to 3), Special Education (3-21 years old), and Supports for Adults (21 and over). In each section, the departments, eligibility, access to services, and financial contributions are discussed. Additionally, parent professional collaboration and helpful hints for success within EI and Special Education are also offered.

Evaluating potential treatments for autism. This portion offers an overview of the current state of autism treatment research and pertinent reviews, as well as resources including the National Standards Project and the Association for Science in Autism Treatment. Additionally, a visual green light, yellow light, red light infographic is provided that lists treatments that are recommended (green light), those that parents should “proceed with caution” towards (yellow light), and those that are ineffective (red light).

Applied Behavior Analysis (ABA). An overview of the science of ABA is given, along with a description of the various skills it can be used to teach, and a list of effective procedures that a comprehensive behavior analytic program might use. A table, that provides “snapshots” of ABA offers parents a look, complete with examples, at what shaping, task analysis, discrete trial instruction, and a functional behavior assessment are. Consumers are also given a description of “What to Look for in a Behavior Analyst”, that describes the certification and attributes of a quality behavior analyst.

What to look for in special education program. A helpful infographic displays various educational programs based on the severity of a child’s disability and the number of students in a particular classroom. Information is discussed regarding the specific components that benefit learners with ASD in an educational environment.

Glossary. A list of acronyms used within the guide.

If you would like to order or download a free copy of this publication, please see www.autismnj.org/document.doc?id=23. Please take a moment to familiarize yourself with the other offerings published by Autism New Jersey <http://www.autismnj.org/publications>

Review of Some Resources About Special Education

Alice Walkup, MS, BCBA
David Celiberti, PhD, BCBA

The Organization for Autism Research (OAR) has created an in-depth guide for parents of children with autism in public schools in the United States. *Navigating the Special Education System* is a resource designed to familiarize parents with the special education system, the rights of their children and recommendations for obtaining services. Relevant laws, such as the Individuals with Disabilities Education Act (IDEA), are reviewed and elaborate on important topics such as entitlement, eligibility, evaluation, procedural safeguards, confidentiality, and discipline. The components of, and differences between, Individualized Education Plans (IEP) and 504 plans are highlighted, and suggestions are provided on how to manage documentation, take notes, and create goals. Templates and checklists are provided for various types of IEP meetings, such as eligibility and annual reviews, in order to introduce parents to the specific decisions that will be made and information they should have at the conclusion of such meetings. The guide also explores common accommodations and available services, such as physical therapy and speech and language therapy. Various decisions and changes will be made as children grow older, and a timeline of services (e.g., early intervention, age of majority) is also addressed. The resource translates abbreviations and terminology that are frequently used in Special Education into everyday language, such as behavior intervention plan and FBA.

Other important topics are discussed, such as moving to a new school district and/or state and how this impacts your child's services. Specific recommendations are provided to assist parents in becoming advocates for their children's education. It is particularly important to note that parents are not always in agreement with school decisions for placement, services, and evaluations. OAR's *Navigating the Special Education System* is highly recommended as a resource for parents in search of the information needed to utilize services available through the special education system and facilitate their child's program well-while working in collaboration with their child's school. This is as many parents may not be familiar with schools' services, and evaluation of the information needed to assist in the process.



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Parents are often overwhelmed with sorting through the overwhelming amount of available information on special education services. Autism New Jersey has come up with a quick checklist that taps into many important features of a quality special education program. Evaluating progress is a critical aspect of your child’s education, and quality programs will utilize objective data collection, systematic measurement, and have open communication between families and the school. Because your child will work with a number of school staff, quality training and supervision in behavior intervention and other evidence-based techniques will have a large impact on your child’s progress. Schools have other services available; some are readily offered and some may need to be requested. Last, but not least, is your reaction as a parent; and *The What to Look for in a Special Education Program* guide lists many important questions which parents should ask themselves and consider when evaluating a particular curriculum, setting, related services, and when gauging satisfaction. We highly recommend that you familiarize yourself with its content.



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Research & Treatment

Learn about Evidence-Based Treatment



For Parents

Guidance for Parents of Children with Autism

Recommended Resources and Books

Resources for Parents

Peggy Halliday, MEd, BCBA

The following websites include milestones checklists, booklets, and a wealth of other helpful information. The contributions have been offered by parent groups as well as professional, medical, scientific, and legal and/or advocacy organizations which are available to meet the needs of families.

American Academy of Pediatrics (AAP)

The AAP is an organization of 64,000 pediatricians committed to the well-being of all infants, children, adolescents, and young adults. The AAP website contains recent information about autism prevalence, links to many external resources and training websites, information about pediatrician surveillance and screening, and early intervention. This site offers great tools and resources for both pediatricians and families. <https://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Autism.aspx>

Association for Behavior Analysis International (ABAI)

The ABAI is a nonprofit professional membership organization whose objective for education is to develop, improve, and disseminate best practices in the recruitment, training, and professional development of behavior analysts. ABAI offers membership to professionals and consumers, which entitles them to the newsletter and other benefits. www.abainternational.org

Association of Professional Behavior Analysts (APBA)

The APBA is a nonprofit organization that is focused on serving professional practitioners of behavior analysis by promoting and advancing the science and practice of applied behavior analysis. The APBA is a nonprofit professional membership organization. Membership is open to professional behavior analysts and others who are interested in the practice of ABA, including professionals from various disciplines, consumers, and students. www.apbahome.net

Autism New Jersey (Autism NJ)

Established in 1965, Autism NJ is now the largest statewide network of parents and professionals dedicated to improving the lives of individuals with autism and their families. Autism New Jersey is a nonprofit agency committed to ensuring safe and fulfilling lives for individuals with autism, their families and the professionals who support them through

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awareness, credible information grounded in science, education, and public policy initiatives. www.autismnj.org

The Autism Science Foundation (ASF)

As well as supporting autism research, the ASF provides information about autism to the general public and serves to increase awareness of autism spectrum disorders and the needs of individuals and families affected by autism. www.autismsciencefoundation.org/

Autism Speaks

Autism Speaks supports global research into the causes, prevention, treatments, and cure for autism and raises public awareness. The website contains information on resources by state, resources for families, advocacy news, and suggested apps for learners with autism. The Autism Speaks 100 Day Kit for Newly Diagnosed Families of Young Children was created specifically for families of children ages 4 and younger to make the best possible use of the 100 days following their child's diagnosis of autism. <http://www.autismspeaks.org>

Behavior Analyst Certification Board (BACB)

The BACB is a nonprofit corporation established as a result of credentialing needs identified by behavior analysts, state governments, and consumers of behavior analysis services. Their mission is to develop, promote and implement an international certification program for behavior analysis practitioners. The BACB website contains information for consumers (including a description of behavior analysis), conduct guidelines, requirements for becoming certified and maintaining certification, and a registry of certificants that can be searched by name or state. www.bacb.com

Cambridge Center for Behavioral Studies

The Cambridge Center for Behavioral Studies website contains behavior analysis resources, a glossary of behavioral terms, online tutorials and suggestions for effective parenting. A continuing education course series is offered through collaboration with the University of West Florida and is designed to provide instruction in a variety of areas of behavior analysis. To utilize all of the features of the website, you must register. www.behavior.org

Centers for Disease Control and Prevention (CDC)

The *Act Early* website from the CDC contains an interactive and easy-to-use milestones checklist you can use to track how your child plays, learns, speaks, acts, and moves ages 3

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months through 5 years. There are tips on how to share your concerns with your child's doctor and free materials that you can order, including fact sheets, resource kits, and growth charts. www.cdc.gov/ncbddd/actearly/index.html

Council of Parent Attorneys and Advocates, Inc. (COPAA)

The Council of Parent Attorneys and Advocates is a national American advocacy association of parents of children with disabilities, their attorneys, advocates, and others who support the educational and civil rights of children with disabilities. The website provides important information about entitlements under federal law. www.copaa.org

Council for Exceptional Children (CEC)

The CEC is an international professional organization dedicated to improving the educational outcomes and quality of life for individuals with exceptionalities. The focus is on helping educators obtain the resources necessary for effective professional practice. Autism is one of many disabilities discussed. www.cec.sped.org

Education Resources Information Center (ERIC)

Sponsored by the Institute of Education Services (IES) of the U.S. Dept. of Education, ERIC provides ready access to education literature to support the use of educational research and information to improve practice in learning, teaching, educational decision-making, and research. <http://eric.ed.gov/>

First Signs

The First Signs website contains a variety of helpful resources related to identifying and recognizing the first signs of autism spectrum disorder, and the screening and referral process. A video glossary is useful in demonstrating how you can spot the early red flags for autism by viewing side-by-side video clips of children with typical behaviors in comparison with children with autism. www.firstsigns.org

Individuals with Disabilities Act (IDEA)

IDEA is a law that ensures services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education, and related services to more than 6.5 million eligible infants, toddlers, children, and youth with disabilities. The IDEA website contains information on early intervention services, local and state funding, and Individualized Educational Plan (IEP) issues including evaluation, reevaluation, and procedural safeguards. <http://idea.ed.gov/>

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National Autism Center (NAC)

The NAC is a nonprofit organization dedicated to disseminating evidence-based information about the treatment of autism spectrum disorder and promoting best practices. Through the multi-year National Standards Project, the NAC established a set of standards for effective, research-validated educational and behavioral interventions. The resulting National Standards Report offers comprehensive and reliable resources for families and practitioners. www.nationalautismcenter.org

National Professional Development Center on Autism Spectrum Disorders (NPDC)

In 2014 the NPDC, using rigorous criteria, classified 27 focused interventions as Evidence Base Practices for teaching individuals with autism. This website allows you to access online modules for many of these practices as well as an overview and general description, step-by-step instructions, and an implementation checklist for each of the practices. <http://autismpdc.fpg.unc.edu/evidence-based-practices>

NIH National Institutes of Health (NIH)

The NIH, a part of the U.S. Department of Health and Human Services, is the primary federal agency for conducting and supporting medical research. Helping to lead the way toward important medical discoveries that improve people's health and save lives, NIH scientists investigate ways to prevent disease as well as researching the causes, treatments, and even cures for common and rare diseases. www.nih.gov

Organization for Autism Research (OAR)

OAR is a nonprofit organization dedicated to applying research to the daily challenges of those living with autism. OAR funds new research and disseminates evidence-based information in a form clearly understandable to the non-scientific consumer. The OAR website contains downloadable autism information for families and professionals, as well as information on studies, research and grants. OAR offers recommendations and worksheets for educators and service providers to assist in classroom planning, and a newsletter, "The OARacle." www.researchautism.org

Parents of Autistic Children (POAC)

POAC is a nonprofit organization that is an educational leader for the New Jersey autism community. The group provides more free training than any other organization. Addition-

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ally, POAC provides recreational and support services to children with autism and their families. www.poac.net

Rethink

The mission of Rethink is to offer parents and professionals immediate access to effective and affordable applied behavior analysis-based treatment tools for the growing population affected by autism spectrum disorders. Their web-based platform includes a comprehensive curriculum, hundreds of dynamic instructional videos of teaching interactions, step-by-step training modules, and progress tracking features. www.rethinkfirst.com/Default.aspx

Virginia Commonwealth University Autism Center for Excellence

VCU-ACE is a university-based technical assistance, professional development, and educational research center for autism spectrum disorder in the state of Virginia. VCU-ACE offers a wide variety of online training opportunities for professionals, families, individuals with ASD, and the community at large. The website contains many useful resources, including a series of short how-to videos demonstrating particular evidence-based strategies. www.vcuautismcenter.org/index.cfm

Wrights Law

Wrights Law is an organization which provides helpful information about special education law, education law, and advocacy for children with disabilities in the USA. The Wrights Law website contains an advocacy and law library including articles, cases, FAQs and success stories, and information on IDEA. www.wrightslaw.com

Zero to Three: National Center for Infants, Toddlers, and Families

This is a national, nonprofit organization which seeks to inform, educate, and support professionals who influence the lives of infants and toddlers. The mission of the organization is to support the healthy development and well-being of infants, toddlers, and their families. The website shares information about the Military Families Project, which supplies trainings, information, and resources for military families with young children. www.zerotothree.org

Suggested Books

Early Intensive Behavioral Treatment

Harris, S.L., & Weiss, M.J. (1998). *Right from the start: Behavioral intervention for young children with autism*. Bethesda, MD: Woodbine House.

Leaf, R., McEachin, J., & Harsh, J.D. (1999). *A work in progress: Behavior management strategies and a curriculum for intensive behavioral treatment of autism*. New York, NY: DRL Books.

Lovaas, O.I. (2003). *Teaching individuals with developmental delays: Basic intervention techniques*. Austin, TX: PRO-ED.

Maurice, C., Green, G., & Foxx, R.M. (2001). *Making a difference: Behavioral intervention for autism*. Austin, TX: PRO-ED.

Maurice, C., Green, G., & Luce, S.C. (eds.). (1996). *Behavioral intervention for young children with autism: A manual for parents and professionals*. Austin, TX: PRO-ED.

Personal Stories

Maurice, C. (1993). *Let me hear your voice: A family's triumph over autism*. New York, NY: Ballantine Books.

Schneider, R.K. (2015). *Silent running: Our family's journey to the finish line with autism*. Chicago, IL: Triumph Books, LLC.

Advocacy, IEPs and Legal Matters

Mayerson, G. (2004). *How to compromise with your school district without compromising your child*. New York, NY: DRL Books, Inc.

Murdick, N., Gartin, B., & Crabtree, T. (2002). *Special education law*. Upper Saddle River, NJ: Pearson Education, Inc.

Behavior Analysis and Autism - User Friendly

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Bailey, J., Burch, M.R., & Burch, M. (2006). *How to think like a behavior analyst*. Mahwah, NJ: Lawrence Erlbaum and Associates.

Buchanan, S.M., & Weiss, M.J. (2006). *Applied behavior analysis and autism: An introduction*. Ewing, NJ: COSAC

Krumins, J. (2009). *One step at a time: ABA and autism in the classroom: Practical strategies for implementing applied behavior analysis for students with autism*. Autism Aspirations.

Newman, B., Reeve, K.F., Reeve, S.A., & Ryan, C.S. (2003). *Behaviorspeak: Glossary of terms in applied behavior analysis (ABA)*. New York, NY: Dove and Orca.

Newman, B., Reinicke, D.R., & Hammond, T. (2005). *Behaviorask: Straight answers to your ABA programming questions*. New York, NY: Dove and Orca.

Behavior Analysis – More academic

Cooper, J.O., Heron, T.E., & Heward, W. (2007). *Applied Behavior Analysis (2nd Edition)*. Upper Saddle River, NJ: Pearson.

Science and Autism Treatment

Foxx, R. M., & Mulick, J. A. (eds.) (2016). *Controversial therapies for autism and intellectual disabilities (2nd ed.)*. New York, NY: Routledge, Taylor and Francis Group.

Freeman, S. K. (2011). *The complete guide to autism treatments: make sure your child get what works!* (2nd ed.). Bellingham, WA: SKF Books, Inc.

Leaf, R., McEachin, J., & Taubman, M. (2008). *Sense and nonsense in the behavioral treatment of autism: It has to be said*. New York, New York, NY: DRL Books.



Association for Science in Autism Treatment
PO Box 1447 Hoboken, NJ 07030
www.asatonline.org