Science in Autism Treatment

Newsletter of the Association for Science in Autism Treatment

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The Association for Science in Autism Treatment is 20 years old this year! We are celebrating our anniversary by launching a campaign designed to increase the visibility of our organization and to increase support for our mission and initiatives. We are asking for your involvement in 20 different ways.

#1 Like us on Facebook: Like ASAT on Facebook and encourage others to do the same so we can surpass our goal to acquire 1,000 more followers in 2018. As a follower on this platform, you can see updates from ASAT, read our Media Watch letters, website announcements, and information about upcoming newsletters and events. We welcome your active participation and encourage you to post comments and share content with your colleagues and friends on Facebook. This only takes a moment and creates valuable exposure for science-based autism treatments worldwide.

#2 Follow us on Twitter: Follow ASAT on Twitter and retweet our posts. We have over 1,500 followers. We regularly send out tweets notifying all followers about any news from ASAT including notification about our latest newsletter, *Science in Autism Treatment*, information about ASAT events, and weekly tweets directing followers to articles and other items of interest. Please follow ASAT on Twitter and join us in our efforts to acquire new followers by tweeting about ASAT to your friends and encouraging all your social contacts to follow us on Twitter.

#3 Share our newsletter with friends and family: Email ASAT's newsletter link to friends and colleagues and encourage them to sign up for our free, informative newsletter. If you do, our 2018 goal of 13,000 subscribers will be quickly realized! Since the summer of 2009, we have published 35 issues of our newsletter, *Science in Autism Treatment,* which now has over 12,000 subscribers in all 50 states and 100 countries worldwide. Archived issues of our newsletter can be found here.

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#4 Volunteer with us: Do you have a special talent, skill set, or some time to offer our organization? ASAT's success rests on the volunteer service of family members, professionals, and community members. Consider volunteering or participating in our externship program. If you are interested, please visit our volunteer page or externship page.

"Working with ASAT has been a great experience. I've had the opportunity to use my strengths and build upon them by writing in the newsletter, learning about grant applications, and collaborating with other team members. Most of all, my experience has enhanced my skepticism and ability to look for the facts related to autism treatment." - Alice Walkup (Los Angeles, California)

#5 Display an ASAT Donation Jar: Do you have or know a business that can display an ASAT Donation Jar? Showcase an ASAT donation jar at various business establishments to help educate consumers and to raise money to support our mission. You can even place a donation jar in your own workplace! ASAT will provide the materials needed (donation jars, an ASAT information card for the jar, business cards, and signage) for any participating business. You can read newsletter articles about participating businesses on our fundraising page also see page 27 here. Your business could get publicized in the ASAT newsletter too!

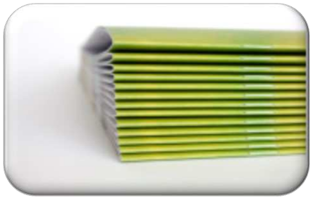
#6 Donate and receive a tax deduction: Do you or someone you know need an end of the year tax deduction? Please encourage friends, family members, and colleagues to donate to the Association for Science in Autism Treatment. Donations in any amount are deeply appreciated. These funds will support a wide array of initiatives including the development and distribution of materials to educate medical professionals about evidence-based treatment for children and adults with autism. Donations can easily be made online through PayPal or by mail.

#7 Seek out a match for your charitable donations: Does your employer match charitable donations? Please consider approaching your employer to find out if your company can match your donation to ASAT. Some employers even make contributions that are twice as much as your individual donation! ASAT would be happy to provide information to your employer or complete applications for matching contributions. Please send requests to donate@asatonline.org.

#8 Join our subscriber drive: Help put our newsletter in the hands of more people. Help us garner new newsletter subscribers by bringing this handy sign-up sheet to your workplace, partner agencies, or meetings. You can scan completed sheets and send via email (subscribe@asatonline.org) or mail to:

ASAT Subscriber Drive— PO Box 1447 | Hoboken, NJ 07030.

#9 Become a sponsor: Show your support for ASAT and enjoy the benefits of being a sponsor, including recognition and newsletter advertisements! We have two types of sponsorship options, each with several levels that provide various incentives to sponsor ASAT: professional sponsors or community sponsors. Please encourage your supervisor or service provider to consider sponsorship.



#10 Help us reach others by displaying ASAT materials: Display our posters, fliers, or other promotional materials in your workplace or other venues, such as coffee shops and bookstores. Doing so will spread the word about ASAT and the

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importance of science in the treatment of autism. Think about how many passersby may benefit from seeing ASAT's message. If you are interested in distributing our materials, please send us an email.

#11 Help us to reach the medical practitioners in your area: Be a proud supporter of our mission by distributing ASAT's information fliers to medical providers and educators in your community. Take some to your next doctor's appointment and be sure to share with your own medical team. If you are interested in sharing material specifically designed for physicians, please send us an email.

#12 Tell others about ASAT: You can help spread ASAT's message of the importance of science in the treatment of autism. At your next professional event or training, include a slide about ASAT at the end of your presentation or distribute our sign-up sheets for our free quarterly newsletter. If you are involved in teaching at the graduate or undergraduate level and want to learn more about how ASAT can support your course offerings, please send us an email.

amazonsmile
You shop. Amazon gives.

#13 Shop at Amazon: ASAT is connected with AmazonSmile. AmazonSmile is the same Amazon you know, same products, same prices, same service. Please support our mission to promote evidence-based, scientifically sound treatments for individuals with autism by choosing us one time and then supporting us every time you make a purchase through Amazon. This link will allow you to purchase on Amazon as usual while donating .5% of eligible purchases to ASAT. We greatly appreciate your participation!

#14 Hold a fundraising event at your workplace: You can build team morale and camaraderie by working together for a great cause (such as the importance of science in autism treatment!). By holding a fundraising event to support ASAT at your workplace you can demonstrate that commitment. It is easy to customize your fundraising event to reflect your workplace values and day to day activities. For instance, you can organize a bake sale. Some of our supporters have held Dress Down Friday and charge a donation fee to participate. If you would like more ideas or need help planning your event contact us by email today at donate@asatonline.org.

Bidding For Good
A FrontStream Company

#15 Bid and bid often: Our next auction via Bidding for Good will be launched in mid September. We will have great items up for bid: autism-related products, signed books, sports and entertainment memorabilia, hotel stays, amusement park, recreational and sports tickets, and so much more! Proceeds directly support important projects, including wider spread distribution of our free quarterly newsletter, promotion of public awareness of science in autism intervention through our website, and expanding our outreach to the parent, journalism, and medical community. We will email you with details!

#16 Donate to our auction: If you would like to donate an item to our upcoming online auction to be launched in mid September, please contact us at: auction@asatonline.org.

#17 Host a Paper Icon Drive: Paper icon initiatives have been successful in banks, retail stores, coffee shops, etc. and typically involve customers making a small donation and placing their name on a paper icon which may be displayed on a wall. ASAT can provide the paper

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icons for your business to sell at the register(s) for a designated time frame chosen by the business. Icons can be sold for $1 or the customer can donate at a level of his/her choice. April is Autism Awareness month, but a paper icon campaign can be launched any time throughout the year.

#18 Advertise With Us: ASAT accepts advertising for the ASATonline.org web site, newsletter and other ASAT publications to offset its operational expenses. Advertising may represent a way for your business to support ASAT while having the opportunity to also promote your organization. To learn more, please click here.

Please be advised that products or services accepted for advertisement by ASAT must be consistent with our mission to disseminate accurate, scientifically-sound information about autism and its treatment and to improve access to effective, science-based treatments for all people with autism. All advertisers are asked to complete the ASAT Advertising Form.

#19 Share specific pages from our website: Did you know you can share specific pages of our website? Whether it is a parent, a medical treatment, or educational professional, or a member of the media who needs to be savvy when reporting on an autism-related story, our website is full of valuable information. At the bottom of every page we make it easy to disseminate knowledge through a variety of social media platforms. We make it easy to share with everyone in your community, as well as locally, nationally, or internationally. Through sharing science-based treatment information with others you may change the life of a child with autism in significant and meaningful ways. Science matters!!!

#20 Got Talent?: We welcome help from those with skills in graphic design, language translation, marketing, google ads, and social media. Help us communicate our information more broadly! If interested, please contact Dr. David Celiberti at dceliberti@asatonline.org.

SCIENCE IN AUTISM TREATMENT TEAM

CONSUMER CORNER

Identifying Applied Behavior Analysis Interventions

Association of Professional Behavior Analysts

What follows is the Executive Summary of a white paper published by the Association of Professional Behavior Analysts (APBA) in May 2017. APBA is a nonprofit organization whose mission is to promote and advance the science-based practice of behavior analysis by advocating for public policies and informing, supporting, and protecting practitioners and consumers. Memberships are available for professionals in behavior analysis and other fields, students, consumers, and Registered Behavior Technicians™. The complete white paper is available to the public and we encourage ASAT readers to disseminate it widely.

Gina Green, PhD, BCBA-D
CEO, APBA | ASAT Co-Founder and Advisory Board Member

Demand for applied behavior analysis (ABA) services has accelerated rapidly since the early 1990s. Although it is only one of many areas of application, much of the increase has been in the realm of interventions for individuals diagnosed with autism spectrum disorder (ASD). Families of people with ASD have played a major role in advocating for public policies to increase the availability of – and funding for – ABA services. Those efforts have produced many benefits; however, the increased demand and funding have also spawned widespread confusion, misunderstandings, and misrepresentations regarding behavior analysis, its applications, and qualifications for practicing ABA professionally.

This white paper aims to dispel some of the most common misconceptions about behavior analysis and to help consumers, members of various professions, funders, and policymakers differentiate ABA interventions from others. It presents key facts about the defining features of the discipline with supporting documentation:

- Behavior analysis is a natural science with concepts, research methods, and principles (natural laws of behavior) that distinguish it from the social sciences.
- The applied branch of the discipline – ABA – originated as a blend of the experimental analysis of behavior and information about human development. From the beginning, ABA incorporated naturalistic as well as structured intervention techniques implemented in a variety of everyday settings.
- Abundant scientific research documents the effectiveness of a large array of ABA procedures for building useful skills and reducing problem behaviors in people with and without specific diagnoses.
- The features of ABA interventions have been defined since 1968.
- The practice of ABA is a profession. Well-established, accredited credentialing programs for practitioners of ABA are managed by the nonprofit Behavior Analyst Certification Board (BACB). Results of extensive job analysis studies conducted by the BACB over the past 15+ years, together with case law and best practices in professional credentialing, have served as the basis for the competencies, degrees, coursework, supervised experience, and professional examinations required to obtain BACB credentials. The requirements parallel those of many other professions. The BACB credentials are recognized in many laws and regulations as qualifications for practicing ABA.

Genuine ABA interventions have all the defining features of ABA and are designed and overseen by appropriately credentialed professionals.

Consumer Corner:

Ten Resources for Consumers to Evaluate Information Sources

Maithri Sivaraman, MSc, BCBA, International Dissemination Coordinator

In an age where sophisticated junk science is the norm, and web offerings that showcase the latest, expensive, so-called cure for autism abound, ASAT has undertaken the important mission to arm parents and professionals with tools to differentiate science-based treatment from quackery. In this Consumer Corner edition, Maithri Sivaraman highlights the following ten resources to help you wade through treatment uncertainty and ensure that your family member afflicted with autism is never exposed to treatments that, at a minimum, lighten your wallet, or in the worst case scenario, are actually harmful to your loved one with autism spectrum disorder.

Sabrina Freeman, Ph.D
Consumer Corner Coordinator

We live in an increasingly evolving digital age. Consumers encounter information from a multitude of sources including traditional media sites, social media, and email. Much of this information is valuable; however not all of them are *sources of information* as much as they are propaganda driven by advertising and clicks. Sadly, the onus of evaluating the overload of media content available to us lies with the consumer. Never before has the need been more urgent for the public to develop their critical thinking skills and distinguish fact from fiction. The following resources will help in sorting the reliable news from the unreliable and aid in making decisions about which sources to trust.

U.S. Department of Health and Human Services - The National Centre for Complementary and Integrative Health of the U.S. Department of Health and Human Services offers tools for finding and evaluating online resources of health-related information. It provides suggestions on five quick questions to ask when visiting a health website to decide if it is a useful resource. Information specific to using complementary approaches to ASD is also available. A thorough Clinical Digest outlines the evidence base (if any) associated with several commonly used complementary health approaches for ASD.

Medline Plus - Medline Plus provides an online guide to healthy web surfing and evaluating the quality of health-related information. The tips mentioned are concise and replete with examples of statements one might encounter on the web along with their implications. It also provides a 16-minute long online tutorial that teaches consumers how to appraise online material.

Fairness and Accuracy in Reporting (FAIR) - FAIR is a media watch group, established in 1986, that offers well-documented criticism of predispositions in the reporting of information. Their article on detecting bias in the media provides a step-by-step guide to identifying and challenging the information that is likely *behind* the headlines. The references to loaded language and misleading headlines are useful reminders to prevent consumers from falling prey to such articles that frequently appear in the media.

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American Press Institute (API) - The American Press Institute provides an article to help consumers figure out what media sources to trust by asking six simple questions. The API emphasizes the nature of the source and the evidence being cited as key factors towards critically thinking about the credibility of media information.

Johns Hopkins Bayview Medical Center - Johns Hopkins Medicine is an integrated global healthcare enterprise and one of the leading healthcare systems in the United States. Their website offers tips on safe internet surfing for health-related information. A presentation to help readers identify the accuracy, authority, bias, currency and comprehension of a sample website is provided. The author calls these guidelines the “ABCs of website evaluation”.

Cornell University Library - Cornell University lists five criteria used for evaluating web pages. It also has a section dedicated to identifying fake news and advertisements designed to look like news. A guide to critical analysis of scientific information sources is available to readers. The library offers tips for simple appraisal of the author and his/her expertise as well as a more detailed evaluation of content quality.

The Digital Resource Center - The Digital Resource Center aims to teach students of journalism to identify reliable information from the daily media tsunami. A free course on News Literacy, created by Stony Brook University, is available on their website. Out of the 14 lessons that are aimed at students of journalism, Lesson 8, Source Evaluation, is useful for news consumers as well. It looks at the standards that consumers can use to weigh the credibility of sources in news reports and explores definitions of self-interest, independence and authority. The course is downloadable for offline use.

Boston College Libraries - The library of Boston College offers a guide to responsible news consumption. The guide is organized into several sections and teaches consumers to evaluate an article before deciding to share it on social media. The guide offers several examples of news stories to distinguish between real and fake ones i.e., straight reporting of facts against advertisements masquerading as news. An extensive list of additional reading and teaching tools is provided at the end of the guide.

Coursera course on “Making Sense of the News” - A free 6-week course is available to anyone interested in evaluating news and making informed judgments. Created by the State University of New York and University of Hong Kong, the course is in English with subtitles in Chinese and Spanish. The syllabus includes modules addressing where one can find trustworthy information and how to apply news literacy concepts in real life.

Santa Clara University’s Fact Checking Guide - An infographic designed to help students of Santa Clara University, and news consumers in general, stay better informed and be skeptical while reading the news. It emphasizes the need to reflect on one’s own personal background and how it might affect the interpretation of a source. It also offers an extensive roster of online resources for checking facts.

The Oxford Dictionary coined the term “post-truth” in 2016 and defined it as *relating to or denoting circumstances in which objective facts are less influential in shaping public opinion than appeals to emotion and personal belief.* Let us all be responsible news consumers and take the effort to look into the evidence in a story without being entrapped by non-truth and post-truth.

October 18 & 19, 2018

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- **Teachers:** access autism-specific best practice for instruction and classroom management.
- Focus exclusively on **financial, legal, and state/federal supports**.
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*Enter the new Adult Autism Research Competition, sponsored by
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Registration is now open!

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IS THERE SCIENCE BEHIND THAT?

Autism and Complementary Alternative Medicine

Kelley L. Harrison, MA, BCBA, LBA-KS
&
Thomas Zane, PhD, BCBA-D

Department of Applied Behavioral Science, University of Kansas

Biomedical complementary treatment approaches, most commonly known as complementary alternative medicine (CAM), are commonly used to treat the behavioral symptoms of autism (e.g., aggression, irritability, hyperactivity; Hendren, 2013). In fact, Höfer, Hoffman, & Bachmann (2017) conducted a systematic review of the literature to determine the prevalence of CAM use and found that 50% of the children with autism spectrum disorder (ASD) used some form of a CAM treatment. CAM may include, but is not limited to, natural products (e.g., vitamins, minerals, melatonin, digestive enzymes), procedures (e.g., neurofeedback, chelation), conventional medications (e.g., antifungals, memantine), or diets (e.g., food restrictions or food products that claim to provide health and medical benefits; Hendren, 2013).

The majority of healthcare providers suggest early intensive behavioral interventions to treat symptoms of ASD as opposed to CAM treatments (Lindly, Thorburn, Heisler, Reyes, & Zuckerman, 2017). In fact, many physicians report a knowledge gap about CAM and its use with ASD (DeFilippis, 2018). However, CAM treatments may be cheaper than other interventions and are often purported to have more immediate and positive effects than other interventions (e.g., behavioral interventions; Lindly et al., 2017).

What Is The Conceptual Link Between ASD And Complementary Alternative Medicine?

The cause of ASD is not completely understood. However, some suggest that ASD has a strong genetic origin and specifically may be caused by a gene-environment interaction (Hendren, 2013). This hypothesis often leads researchers to search for biochemical or physiological differences between individuals with and without ASD that may be responsible for the development of ASD.

There have been several biochemical and physiological differences suggested to correlate with ASD such as hormonal abnormalities, immune abnormalities, inflammation, oxidative stress, mitochondrial dysfunction, and free fatty acid metabolism. CAM treatments claim to treat the behavioral symptoms of ASD by correcting the biochemical or physiological state of the individual with ASD (Hendren, 2013). For example, some research suggests that individuals with ASD may produce abnormal levels of melatonin, a neurohormone that cause drowsiness and sets the body's sleep clock (Rossignol & Frye, 2011). Often, individuals with ASD experience sleep problems, and so a common CAM treatment is an increased intake of melatonin (Hendren, 2013).

What Is The Scientific Evidence Of Complementary Alternative Medicine Use For Autism?

Research on CAM treatments for ASD is still in its very early stages, with some treatments beginning to show promise, others beginning to appear ineffective, and still others associated with serious medical risks (Hendren, 2013). The National Center for Complementary and Integrative Health (NCCIH) was established in 1991 under the National Institute of Health (NIH) to promote the scientific study of CAM treatments (Levy & Hyman, 2015). NCCIH's mission is to "define, through rigorous scientific investigation, the usefulness and safety of complementary and integrative health interventions and their

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> **The FDA specifically warns against the use of chelation therapy, hyperbaric oxygen therapy, and detoxifying clay baths because of the improper claims about these products and the significant health risks associated with these products.**

roles in improving health and health care" (NCCIH, 2016). Overall, NCCIH reports the following findings with respect to some popular CAM treatments:

(a) No cure has been identified for ASD, but intensive behavioral therapy and early intervention can greatly improve a child's development.

(b) There is very little high quality research on CAM for ASD.

(c) Melatonin may help with sleep problems in people with ASD.

(d) It is unclear if omega-3 fatty acids, acupuncture, mindfulness-based practices, massage therapy, special diets, and hormone oxytocin improve ASD symptoms, and therefore (these) should not be used in place of conventional treatments.

(e) There is no scientific evidence that secretin, hyperbaric oxygen, chelation, or antifungal agents improve ASD symptoms and these treatments may be dangerous (NCCIH, 2017).

In addition to the NCCIH, the Food and Drug Administration (FDA) has also released statements concerning the use of CAM treatments for ASD. Specifically, the FDA attempts to stop companies from making false claims about their products use as a treatment or cure for ASD, stating, "There is no cure for autism. So, products or treatments claiming to "cure" autism do not work as claimed…Some may carry significant health risks" (U.S. Food and Drug Administration, 2017). The FDA has approved some drugs to help manage symptoms of ASD. Specifically, the use of antipsychotics such as risperidone and aripiprazole has been approved to treat irritability. Additionally, the FDA specifically warns against the use of chelation therapy, hyperbaric oxygen therapy, and detoxifying clay baths because of the improper claims about these products and the significant health risks associated with these products (U.S. Food and Drug Administration, 2017). Finally, it should be noted that no drug has FDA's approval for the treatment of autism itself or for the core symptoms of autism (i.e., social communication deficits, restricted/repetitive behaviors); rather, the approved drugs treat behavioral symptoms correlated with ASD (e.g., irritability; DeFilippis, 2018).

Overall, the experimental validity for any CAM treatment ranges. Some treatments appear promising (e.g., melatonin for sleep), while others can be outright rejected as an effective treatment (e.g., secretin, hyperbaric oxygen). Most, however, simply have insufficient evidence available to determine validity (e.g., modified diets, immune therapy, vitamin and fatty acid supplements). Therefore, there is a clear need for more methodologically rigorous studies to understand the effects of CAM treatments and provide guidance for families and clinicians (Whitehouse, 2012).

Future Research

When all available evidence is taken together, there are no CAM treatments that are ready for general use (Hendren, 2013). In order for CAM treatments to be safely, efficiently, and effectively used, future research is necessary. This research should be experimentally rigorous and empirically sound. That is, research should be peer-reviewed, methods should exclude biases (e.g., double blind, single-subject design), consistent dosing should be used across participants, and outcome measures should be valid (i.e., measure what they intend to measure). Additionally, research should take into account other treatments that are implemented concurrently with the CAM treatment such that effects of the treatment can be isolated from the CAM treatment in question and not attributable to other outside treatments. Finally, because CAM treatments target abnormal biochemical and physiological processes (which are not present in all individuals with ASD and may only be present for a given period of time for a particular individual), research should utilize participants whose biomarkers match the purpose of the CAM treatment to be sure the intervention is targeting an active biomedical process (Hendren, 2013). For example, when evaluating the use of melatonin for sleep prob-

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lems, participants should include individuals who do not produce enough melatonin naturally. Only when substantial empirical evidence suggests a CAM treatment is safe and effective should parents or caregivers consider its use, and even then parents and caregivers should always work closely with medical practitioners to select and evaluate an appropriate treatment.

Parents, consumers, and caregivers should also explore treatments alternative to CAM. There are many evidenced-based strategies that exist for a myriad of learning, social, and behavioral issues related to ASD (e.g., early intensive behavioral intervention; Klintwall, Eldevik, & Eikeseth, 2015). Consumers should first consider which of these methods could be tried before contemplating CAM.

What Is The Bottom Line?

The current state of research surrounding CAM treatments is sparse, with most treatments requiring more in-depth study, and others demonstrated to be ineffective and/or dangerous (Levy & Hyman, 2015). Therefore, parents, caregivers, physicians, and clinicians should be extremely cautious when using or recommending CAM treatments.

> ”
> **Bottom line: the current state of research surrounding CAM treatments is sparse, with most treatments requiring more in depth study, and others demonstrated to be ineffective and/or dangerous.**

Conceptually, CAM treatments usually have a clear physiological rationale such as an increased intake of melatonin to correct sleep problems. However, as with any treatment, caregivers should always consider the literature available surrounding a given treatment. They should ask, “Is the information available from peer-reviewed scientific sources or is it anecdotal in nature?” “Are the methods for testing described in detail such that it can be determined if any biases exist?” “Are the outcome measures of treatment effects valid (i.e., do they measure what they say they measure)?” Although the conceptualization surrounding a given treatment may be sound, the treatment itself may be ineffective and could potentially be dangerous (Levy & Hyman, 2015).

As with any treatment, medical monitoring is very important. Caregivers should always consult a health care professional before implementing a CAM treatment and inform their child’s primary physician of all CAM treatments they are implementing. Unfortunately, in a 2015 survey on the use of CAM treatments for children with ASD, families reported that they rarely ask physicians for information on CAM treatments. Instead, almost two-thirds of the families reported finding internet-based communities and websites as their first source for medical information. When the families were asked why they do not report CAM treatments to physicians, the most common responses included a perception of a lack of knowledge by the physician, a lack of time for discussion, not seeing the necessity of reporting these treatments, and a concern regarding disapproval by the physician (Levy & Hyman, 2015). This finding is even more concerning because physicians often report a knowledge gap concerning CAM treatments and their use with ASD, as well as a concern about potential conflicts between themselves and parents surrounding different beliefs about the use of CAM treatments for ASD (DeFilippis, 2018). However, both of these findings (i.e., family’s tendencies to rely on internet-based information and physician’s hesitation to discuss CAM treatments) further suggest the need for future research before implementation of CAM treatments is considered.

Finally, parents and caregivers should be suspicious of products that claim to treat a wide range of diseases, avoid personal testimonials, be weary of “quick fixes” and “miracle cures,” and instead seek scientific evidence (U.S. Food and Drug Administration, 2017).

References

DeFilippis, M. (2018). The use of complementary alternative medicine in children and adolescents with autism spectrum disorder. *Psychopharmacology Bulletin, 48*, 40-63.

Hendren, R. L. (2013). Biomedical complementary treatment approaches. *Child and Adolescent Psychiatric Clinics of North America, 22*, 443-456.

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(Continued from page 12)

Höfer, J., Hoffmann, F., & Bachmann, C. (2017). Use of complementary and alternative medicine in children and adolescents with autism spectrum disorder: A systematic review. *Autism, 21*, 387-402.

Klintwall, L., Eldevik, S., & Eikeseth, S. (2015). Narrowing the gap: Effects of intervention of developmental trajectories in autism. *Autism, 19*, 53-63.

Levy, S. E., & Hyman, S. L. (2015). Complementary and alternative medicine treatments for children with autism spectrum disorders. *Child and Adolescent Psychiatric Clinics of North America, 24*, 117-143.

Lindly, O. J., Thorburn, S., Heisler, K., Reyes, N. M., & Zuckerman, K. E. (2017). Parents' use of complementary health approaches for young children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*(5), 1-16.

National Center for Complementary and Integrative Health. (2016, June). Complementary, alternative, or integrative health: What's in a name? Retrieved from: https://nccih.nih.gov/health/integrative-health.

National Center for Complementary and Integrative Health. (2017, September). Autism. Retrieved from: https://nccih.nih.gov/health/autism

Rossignol, D. A., & Frye, R. E. (2011). Melatonin in autism spectrum disorders: A systematic review and meta-analysis. *Developmental Medicine and Child Neurology, 53*(9), 783-792.

U.S. Food and Drug Administration. (2017, April). Autism: Beware of potentially dangerous therapies and products. Retrieved from: https://www.fda.gov/ForConsumers/ConsumerUpdates/ucm394757.htm

Whitehouse, J. O. (2013). Complementary and alternative medicine for autism spectrum disorders: Rationale, safety, and efficacy. *Journal of Pediatrics and Child Health, 49*(9), 438-442.

FROM THE ARCHIVES

DISCUSSING CONCERNS WITH FAMILY MEMBERS

Peggy Halliday, MEd, BCBA
David Celiberti, PhD, BCBA-D

When you are worried that someone in your family may have autism spectrum disorder (ASD), it can be difficult to know how to share your concerns or observations with them or their parents in a supportive manner. Weighing the risks and benefits to having the conversation, communicating with a non-judgmental approach, and knowing what you can do to support your loved ones will be highly beneficial. Early detection and intervention are crucial; below you will find some considerations and recommendations from Peggy Halliday and David Celiberti that may assist you in planning the conversation.

Caroline Simard, MS, BCBA
Newsletter Content Coordinator

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

Answered by:
Peggy Halliday, MEd, BCBA &
David Celiberti, PhD, BCBA-D

It is natural to be unsure of how to share your concerns with your grandson's parents. As is the case with many concerned family members, you may worry that such a discussion will not be well received. You may fear that it can cause some discomfort or tension in your relationship. If autism is a possibility, you would not want to delay screening which could result in a referral for an evaluation and services. Waiting may waste valuable time during which intervention can be most beneficial for your grandson. Even knowing that better outcomes can come from early diagnosis and intensive intervention, it still may be difficult to talk to your son and daughter-in-law if they have not expressed their concerns to you directly.

As a grandparent, you have already raised at least one child, so you probably have a good sense of what may be typical behavior and what is not. You may feel that your grandson is not making expected gains or may appear delayed in some areas such as communication or play compared to other children his age. Also, you may not have day to day contact with your grandson, so slower development of skills may be more obvious to you. These impressions may create a sense of urgency for you.

There are several important considerations in planning for this discussion. Perhaps the most important consideration is to weigh the pros and cons of talking to your son and daughter-in-law vs. the pros and cons of not talking to them. Although it may seem prudent to wait, the risk of delay to diagnosis and treatment is potentially much greater than the risk of harming the relationship.

The way in which you approach your son and daughter-in-law will depend in large part on the quality of your relationship and on the nature of how you communicate with one another. In your relationship, you may already discuss difficult issues frequently and easily. On the other hand, this may not describe the

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type of relationship you have at all. Regardless, it is important that you bring this up from a place of love and concern, rather than judgment and blame. Many parents who have been carefully and respectfully approached by a relative later admit that they already had concerns of their own, and it was a relief to discuss them with someone else close to their child.

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

Planning Ahead

1. Plan your discussion ahead of time. Take some time to think about what you want to share and how you want to frame your concerns. It may be helpful to preview a screening tool such as the M-Chat.

2. Find a time and place when you will not be interrupted. It may be best when the child is with another caregiver.

3. You might begin by commenting on the child's strengths and praising the parents' love and dedication to their child. It is important not to appear judgmental or focused only on the concerns.

4. The role you take in the child's life depends, of course, on geographic proximity, but be poised to offer concrete, practical help whenever possible. For example, you might offer to babysit siblings while parents pursue evaluation of the child, or offer a respite weekend of childcare so that your son and daughter-in-law might have time to discuss the situation without interruption.

5. Whatever assistance you offer, the important thing is that your grandson's parents perceive it to be helpful, so try and gauge their reactions carefully.

Having the Conversation

1. Try to keep the conversation free flowing. You may want to ask a few questions that will allow the parents to express their concerns if they have them. For example, "I noticed that Billy became very upset when the phone rang. Does the phone ringing bother him?" or "Does he seek you out when he is upset?".

2. Avoid labels and technical terms, which may trigger fear or upset from the parents. Focus instead on discussing milestones, which are observable indicators of a child's development and accomplishments.

3. In some cases, it may be beneficial to think about the discussion as a series of tiny conversations. This approach would be more appropriate if you have frequent contact with your son or daughter-in-law. It may then be helpful to share some observations that provide a backdrop for later discussion. For example, "Little Peter seems overwhelmed by loud noise." or "I have noticed that he does not seem to know how to use words to get his needs met."

4. It may also be helpful to discuss observations surrounding problematic or absent social interactions with peers or siblings.

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

Other Considerations

1. Most parents start to become concerned that something may be wrong with their child between the ages of 12 and 18 months. If the parents are beginning to realize a potential problem exists, you want to gently urge them not to delay screenings and/or evaluations. It may also be helpful to have contact information on hand within your local state/town. Often parents can feel overwhelmed due to not knowing what the first step would be. Having this information ready for whom to contact and how to schedule a screening may reduce some of the stress in hearing the news.

2. You should never take for granted that developmental concerns will automatically be addressed during routine visits to the pediatrician. Some-

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times they are not. Refer parents to good quality resources they can explore on their own, such as our website. We emphasize the word "good" as there is a tremendous amount of misinformation about autism both in the media and on the Internet, particularly many false promises about autism treatment. We share some of these resources below. The most helpful websites at this stage are typically the ones that discuss developmental milestones. Parents often know when to expect their infants and toddlers to sit up or take their first steps, but they do not know when they should begin to speak in 2-3 word statements, point to things they notice or want, imitate gestures, or show interest in another child.

3. If the child is in a daycare, his teachers and directors have relevant information about his progress. They should be keeping records on how the child is developing in different areas such as social interaction, verbalization, etc. They are also a good resource to use to help evaluate your child in a school setting.

The following websites include milestones checklists, booklets, and charts, and a wealth of other helpful information.

★ **Association for Science in Autism Treatment (ASAT)**: On the ASAT website, you will find an extensive list of proposed treatments for autism - each treatment has a scientific research summary and recommendations based on level of effectiveness in treating autism; guidelines and articles on how to select the best treatment for your child; answers to frequently asked questions by parents and caregivers; and links to helpful sites and other science-based organizations.

★ **Centers for Disease Control and Prevention**: The Act Early website contains an interactive and easy-to-use milestones checklist you can create and periodically update for children ages three months through five years, tips on sharing concerns with the child's doctor, and free materials you can order, including fact sheets, resource kits, and growth charts.

★ **First Signs**: The First Signs website contains a variety of helpful resources related to recognizing the first signs of autism spectrum disorder, and the screening and referral process. There is a directory of local resources for at least eight states, and that number is likely to increase over time.

★ **American Academy of Pediatrics (AAP)**: The AAP website contains information for families, links to many other websites, information about pediatrician surveillance and screening, and early intervention. This site contains great tools for pediatricians, as well as parents.

★ **Autism Speaks**: The Autism Speaks website includes an Autism Spectrum Disorder Video Glossary of clips designed to help parents and professionals learn more about the early 'red flags' of autism, information about how autism is diagnosed, and a resource library. They also offer a free 100 Day Kit designed to help families of newly diagnosed children make the most of the first 100 days following a diagnosis of autism.

In summary, we think it is commendable that you desire to share your concerns in a sensitive way with your son and daughter-in-law. We hope that this advice has been helpful to you, and we wish the best for your grandson's future. If your concerns are well founded and your grandson receives a diagnosis of autism, we recommend that your family learn all they can about applied behavior analysis, the treatment for autism that has the most compelling scientific support. The ASAT website, of course, would be an excellent resource at that point as well.

Please visit our Clinical Corner section to read articles related to young children with autism:

- How do I teach game playing skills to children with autism?
- How do you teach an 18-month old with autism?
- What are some strategies for getting my child to go to bed and sleep through the night?
- How can I help my child learn to play with a friend during play dates?
- How likely is it that I could have another child with autism?

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- How do I explain my decision to use science-based treatments for autism when friends and relatives often insist I try something new?

- How to manage the impact of child with a disability on siblings?

Please read an overview of early intensive behavioral intervention and visit our Research Synopses section to learn more about early intervention research. A few links are shared below:

- Behavioral intervention in mainstream preschool settings

- EIBI in Community Settings: Public preschool and kindergarten

- A systematic review of early intensive intervention for autism spectrum disorders

- Early intensive behavioral intervention: Outcomes for children with autism and their parents after two years

- Systematic review of early intensive behavioral interventions for children with autism

Shout Outs, Accolades, and Appreciations

EFFORTS TO EXPAND OUR SUBSCRIBER BASE
ELENA M. ESCALONA, MSED,
SUBSCRIBER DRIVE COORDINATOR

ASAT would like to recognize those individuals and organizations who strive to support our efforts to garner more subscribers. Specifically, we would like to thank and send a "shout out" to the following supporters:

- Our heartfelt thanks to **The Kendall Centers & Therapeutic Pathways, Inc.**, one of our Benefactor level sponsors, for displaying ASAT's fliers and information on the television monitors throughout all sites reaching hundreds of families, staff, and other professionals. Please visit their website at www.tpathways.org.

- We are very grateful to **Scott Stiefvater** from the **Slomoff Consulting Group** for donating his time and talent to help us create a soon to be released Public Service Announcement (PSA) about ASAT. Scott's firm takes a very innovative and personalized approach to speaker coaching. Contact him to learn more!

- A special thank you to **Steven Petrone**, Vice President of Operations/ **Pamal Broadcasting Hudson Valley** Market/Program Director WHUD-FM who created two 30 second PSAs about ASAT. These have been running extensively on several Hudson Valley, New York radio stations (WHUD-FM, WSPK-FM, WXPK-FM, WBPM-FM and AM combination WBNR-WLNA-WGHQ-AM). The 1st PSA, which referenced Autism Awareness Month, aired 4/23-4/30, followed by the 2nd PSA which will run for the remainder of the year. We are very grateful for this exposure!

If you would like to share information about any initiatives you have undertaken to help us acquire new subscribers to *Science in Autism Treatment*, please write us at subscribe@asatonline.org. We appreciate your support!

RESEARCH SUMMARIES

A Randomized Trial of Social Skills Groups at School

&

The Effect of Oxytocin Nasal Spray on Social Interaction Deficits

In this issue of SIAT, we summarize two studies. The first compares school-based social skills interventions for students with autism spectrum disorder (ASD). The second looks at the effects of oxytocin nasal spray on social interaction in children with ASD. We hope this is useful information.

Karen Fried, PsyD, BCBA-D
Research Synopses Co-Coordinator

Children with autism spectrum disorder and social skills groups at school: A randomized trial comparing intervention approach and peer composition

Kasari, C., Dean, M., Kretzmann, M., Shih, W., Orlich, F., Whitney, R., ... & King, B. (2016). Children with autism spectrum disorder and social skills groups at school: A randomized trial comparing intervention approach and peer composition. *Journal of Child Psychology and Psychiatry*, *57*(2), 171-179.

Reviewed by: Allison Hawkins, Rutgers University, Graduate School of Applied and Professional Psychology

Why research this topic?

School-aged children with autism spectrum disorder (ASD) frequently struggle with making friends and understanding social expectations. In order to improve their social skills, many of these children participate in social skills groups both in and out of school. Currently, the research on school-based social skills groups for children with ASD is lacking because most studies take place in clinic settings. The benefits of such groups may be limited for children with ASD who are in general education because these children tend to be the only student with ASD in their classroom, which makes it difficult to find friends with similar interests. To address the need for evidence-based, effective, school-based social skills interventions for students with ASD, Kasari and colleagues compared different types of social skills groups in schools.

What did the researchers do?

Researchers from four universities and research centers conducted the study in local public schools. The participants were 137 individuals with ASD, ages 6-11 years. The participants were randomly assigned to participate in one of two types of social skills groups – SKILLS or ENGAGE. Both groups took place at school during morning or lunchtime recess and occurred in 2, 30-45 minute sessions per week for 8 weeks.

The SKILLS group contained only children with ASD and focused on social skills lessons, which were delivered by a graduate research assistant, with free time at the end of every session. During each session, participants earned points on a punch card that they could exchange for weekly rewards from a Treasure Box. The ENGAGE group included both children with ASD and their neurotypical peers and focused on peer engagement by allowing the children to choose activities to play during each group. Graduate research assistants facilitated the activities when needed, but mostly allowed the children to play independently, when possible.

What did the researchers find?

The researchers found more positive outcomes in SKILLS than ENGAGE. Thus, adult-led, didactic social skills training for children with ASD appeared more effective for improving peer acceptance and engagement on the school playground than a naturalistic intervention that grouped children with ASD

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with neurotypical peers. This is important because clinic-based, lecture-style social skills groups have previously been unsuccessful at helping participants generalize their skills to school, where most interactions with peers take place.

What are the strengths and limitations of the study?

An important strength of this study is the inclusion of children from across the country, which suggests that the SKILLS intervention could be utilized successfully in many different schools. Limitations of this study include loss of participants due to teachers or students changing classrooms. Additionally, the interventions were complex, making it difficult for the researchers to pinpoint exactly what caused the results.

What do the results mean?

Despite these limitations, the results of this study suggest strong benefits of using a lecture-based social skills group with students with ASD in schools, and that such groups should be adopted more widely and studied more frequently.

The Effect of Oxytocin Nasal Spray on Social Interaction Deficits Observed in Young Children with Autism: A Randomized Clinical Crossover Trial

Yatawara, C.J., Einfeld, S.L., Hickie, I. B., Davenport, T. A., & Guastella, A. J. (2015). The effect of oxytocin nasal spray on social interaction deficits observed in young children with autism: A randomized clinical crossover trial. *Molecular Psychiatry, 21(9)*, 1225-1231.

Reviewed by: Catherine Kishel, Rutgers University, Graduate School of Education

Why research this topic?

Social interaction deficits are considered a core symptom of autism spectrum disorder (ASD), but effective treatments for these deficits are limited. Some medications may improve behavior problems that are sometimes associated with ASD (e.g., aggression or over-activity), but there is little evidence for medications effective in treating the core social symptoms of ASD. Behavioral interventions offer significant improvements, but are often time consuming and costly. The hormone oxytocin is associated with social understanding and behavior in typically functioning adults, leading to the possibility that it may be an effective treatment for social symptoms experienced by children with ASD. Initial studies found that oxytocin administered via nasal spray to adults and youth with ASD (aged 12-19) improved emotion recognition. The current study sought to determine the effects of oxytocin nasal spray on social interaction in children ages 3-8 with ASD, since prior research indicates that interventions provided early in childhood offer the best chances for long-term improvement.

What did the researchers do?

The researchers recruited 31 children with ASD ages 3-8 years and randomly assigned them to one of two treatment conditions: 1) oxytocin nasal spray for the first phase of the experiment followed by 2) placebo in the second phase (A-B, 15 participants) or the reverse (B-A, 16 participants). Each phase lasted five weeks, with a four-week period between phases to prevent carryover effects. Neither the participants, their parents, nor the experimenters knew which children were receiving which nasal spray at any time during the experiment; this was done to control for potential bias in the results. All families completed pre-test screening assessments, including the ADOS (Autism Diagnostic Observation Schedule), SRS (Social Responsiveness Scale), DBC (Developmental Behavior Checklist), RBS-R (Repetitive Behavior Scale - Revised), and CSQ (Caregiver Strain Questionnaire) to obtain baseline measures of symptom severity and family burden before phase 1 and again before phase 2. The researchers then looked for a change in these measures, as well as clinician global improvement ratings, after the children experienced both phases of the experiment.

What did the researchers find?

The researchers found that, on average, children improved significantly more in parent-rated social responsiveness (SRS) and clinician global improvement ratings after receiving oxytocin than after receiving placebo. There were no significant differences between oxytocin and placebo for severity of

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ASD symptoms (ADOS), behavior problems (DBC), or repetitive behavior (RBS-R-P), or for family burden (CSQ). Interestingly, 90% of participants improved on the SRS between pre- and post-test results after receiving oxytocin, while 77% of participants demonstrated improvement between pre- and post-test results after receiving the placebo spray. Conversely, no participant worsened following oxytocin administration, but 10% did so after receiving placebo. No significant differences were found between oxytocin and placebo on adverse reactions experienced by children (adverse reactions included thirst, increased urination/constipation, and hyperactivity and aggression).

What are the strengths and limitations of the study?

A strength of the study is that it is the first double-blind, randomized, placebo-controlled, crossover clinical trial investigating the effects of oxytocin nasal spray on the social behavior of young children diagnosed with ASD. Oxytocin was found to be well tolerated by the children and easy to administer. Limitations include the small sample size (31 children), the inclusion of children who were taking other psychotropic medications during the experiment, and reliance on parent report as an outcome measure. In addition, many children were excluded because they did not accept nasal spray administration, limiting the generalizability of the results and potential application of this intervention.

What do the results mean?

This study suggests that oxytocin nasal spray may improve social symptoms in young children with ASD. However, these results need to be confirmed in larger studies that include a representative sample of young children with ASD. Nasal administration of oxytocin is an example of the potential for development of a medical treatment for social impairments in children diagnosed with ASD.

CLINICAL CORNER

Leisure Skills for Adults with Autism

Megan McCarron, MS, BCBA
Milestones Behavioral Services

Establishing a broad repertoire of leisure activities for individuals with autism spectrum disorder (ASD) can be incredibly challenging for parents and other caregivers. In this installment of Clinical Corner, Megan McCarron, a board certified behavior analyst (BCBA) with over 20 years of experience in applied behavior analysis (ABA), presents a process for identifying, assessing, and incorporating leisure activities for individuals on the spectrum.

Kate Fiske, PhD, BCBA-D
Clinical Corner Co-Coordinator

I am a BCBA working in an ABA Teaching Home. I am adept with teaching play skills to younger children but would like some guidance on assessing interests and helping young adults develop hobbies that they can pursue in an independent and meaningful manner.

Answered by:

Megan McCarron, MS, BCBA
Milestones Behavioral Services

This is a very important question. There is an abundance of research on how to teach leisure activities using instructional methods such as modeling, video modeling, and activity schedules (Blum-Dimaya, Reeve, Reeve, & Hoch, 2010; Carlile, Reeve, Reeve, & DeBar, 2013; Chan, Lambdin, Van Laarhoven, & Johnson, 2013; MacDuff, Krantz, & McClannahan, 1993), moreover, it is vital that careful thought and planning be put into selecting individualizing leisure activities. This can be challenging given that what one person considers to be leisure, another individual could see as work.

Let's start with a basic definition. Google dictionary defines leisure as, "Free time; use of free time for enjoyment; opportunity afforded by free time to do something." A key phrase in this definition is, "for enjoyment." When selecting leisure activities for an individual, a key focus should be to determine their preferences and look for ways to build on those.

Typically, one's interests are developed over time via exposure to and interaction with new and varied people, places, and activities. Exposure usually occurs over the course of life without much forethought, planning, or overt teaching, resulting in interests that shift and change over time. Unfortunately, this is often not the case for individuals with autism spectrum disorder (ASD).

There are two key deficits within the diagnostic criteria for ASD that are likely to impact individuals' exposure to and interaction within varied leisure activities. First, persistent limitations in social communication and social interaction can hinder an individual's ability to request access to items and activities, to fully engage in activities, and/or to express one's level of interest at any point throughout the

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activity. Second, the presence of restricted, repetitive patterns of behavior, interests, or activities may prevent an individual from exploring novel items or activities.

Individuals' difficulty making or expressing choice, lack of social reciprocity and initiation towards activities, and potential unpleasant reactions to change and novel stimuli can lead those around them to consciously or unconsciously limit exposure to new and varied items and activities. Limited interests or those that are markedly different from those of same-aged peers make it that much more difficult to determine ways to expand and develop interests. As a result, careful thought and planning are required to help individuals with autism develop, access, and engage in meaningful leisure activities.

Finding Leisure Activities

Given that there is an unending number of items or leisure activities that could be assessed, it is important to make the most of your assessments by narrowing down the field to things that are likely to be of interest before conducting your assessments. A few of these approaches are as follows:

- Expand upon current interests. Identify known preferences. Ask caregivers, teachers, siblings, or others who spend time with the individual to complete an interview, checklist or other type of survey. Create your own questions or use published materials such as the Reinforcer Assessment for Individual with Severe Disabilities (RAISD; Fisher, Piazza, Bowman, & Amari, 1996). Do not immediately discount unusual or idiosyncratic interests. Look to see if there are groups in the community or online that share that interest, you may be surprised. If necessary, teach a "Time and Place" (i.e., when and where it is okay) to engage in preferences that may be annoying to others or are socially stigmatizing. Examples:

Known Interest	Expansion Ideas
Looking at photographs	Taking photographs, uploading photographs to computer, editing photographs, creating digital album, printing, photographs, scrap-booking, photography clubs/groups, etc.
Comic books	Attending Comic Con, visiting comic book stores, participating in community-based or online comic book clubs
Chess	Joining chess clubs (school, community) Playing online

- Select novel activities that contain components of already preferred activities. Identify common features of known preferences, and then identify novel items or activities that contain the same or similar features. Examples:

Known Interests	Key Feature	Novel Items
Flicking things **Strings** **Flags**	Waving or fluttering motions	Ribbon dancing Exercise ropes/ Battle Ropes Kites
Thomas the Tank	Trains	Puzzles with Thomas Watch other train videos Model trains Electric trains w/ tracks

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- Or, make modifications to existing activities to incorporate the preferred feature of other preferred activities. Examples:

Known Interests	Modification
Specific Characters	Add characters to board games by using stickers, changing out playing pieces Read books containing those characters Create your own puzzles or playing cards Craft / building projects that incorporate the character

- Alternatively, pair a known interest with a compatible novel activity. Examples:

Known Interests	Pair with novel compatible activity
Music	Listen to music while exercising Dance while listening to music Garden while listening to music

- Identify shared interests. In addition to identifying activities by exploring and expanding upon current interests of the individual, it can be worthwhile to identify interests of the people the individual spends a lot of time with and activities available in the individual's school, home, and local community. These activities, if also preferred by the individual with ASD, will offer up the opportunity for social interaction with others.

Assessing Activities

Once potential activities are selected, assessments can be conducted to determine how preferred the activities are. While preference assessments are commonly used and talked about in terms of finding reinforcers (Carr, Nicolson, & Higbee, 2000; Graff & Karsten, 2012), they are equally useful for assessing preference levels for potential leisure activities. There are various methods of conducting preference assessments (e.g., paired choice, multiple stimulus with replacement, multiple stimulus without replacement [MSWO]; Toner, 2014). Initially, free operant assessments are very helpful in terms of assessing potential leisure activities. These can be conducted in the natural environment or a contrived and enriched setting.

Free operant preference assessments can be conducted through direct observation by providing free access to activities without demands, time limits or requirements to use items in a predetermined manner (unless it is a safety issue). Assessments can be conducted in either a natural or contrived setting, as described below (Toner, 2014; Chazin & Ledford, 2016).

Direct natural environment	Direct observation in contrived/enriched setting
Mall, school, gym, park, etc. Go to the environment and observe where the individual goes and what they do.	Gather items or activities you think may be of interest in one area. Allow the individual to explore the area.
Collect data on: • Which items/activities the individual interacts with • Duration of each interaction • Can be helpful to note the individual's observable signs of positive affect during interactions, such as smiles or laughter • If the individual interacts with an item in an unexpected or unusual manner, make note of what he or she did	

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Once the free operant assessment data have been collected and ranked in order of which activities were engaged with the most (e.g., by calculating a percentage of time of the observation in which the student engaged in each activity), subsequent paired choice preference assessments or MSWO assessments could be conducted to better assess the individual's relative preference for activities. With this information, you can make an informed choice about what activities are likely to provide "enjoyment" and thus fit the definition of leisure.

Selecting Teaching Targets for the IEP

It is important to help an individual build a repertoire of activities that can be used to fill the various functions of leisure. Therefore, the activities chosen as a focus of teaching should cover a variety of leisure situations.

- Social Activities (any activity done with another person).
- Individual Activity (any activity that can be done alone).
- Health and Fitness.
- Longer duration activities.
- Short duration activities that can be done while waiting (looking at books, magazines, music on phone, etc.).

Some activities may be adaptable enough to be used across several leisure functions. For example, listening to music can be a social or individual activity; it can easily be paired with a variety of health and fitness activities and can be used for short or long durations.

In addition to selecting specific activities/skills for leisure, it is advisable to include an objective in a student's IEP that targets the individual's exposure to leisure activities, such as "Sampling Leisure Activities." The goal of this objective would be to have the student continue to try out new activities over three to four opportunities to further expose them to new activities that may be of interest. During the sampling sessions, staff should collect data on duration of engagement, observable signs of affect, and any skill deficits that inhibit engagement.

Considerations for Increasing Functional Independence in Leisure

While identifying preferred activities is a major part of building a leisure repertoire, there are a whole host of skills that, when taught effectively, can increase an individual's ability to access and engage in leisure activities as independently as possible.

- Ensure the individual has an appropriate and effective means of communication. An essential skill, regardless of the individual's vocal verbal ability, is teaching an appropriate way to request access to activities, especially those that are not readily available in the current environment such as requesting to go to the mall or to a specific store (Schneiter & Devine, 2001). Equally important, but often overlooked, is the ability for an individual to appropriately decline participation and/or end an activity when the activity is not preferred.
- Teach prerequisite skills. If a student shows interest in an activity but is not able to fully engage in the activity, it may be necessary to teach the individual specific prerequisite skills. Examples:

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Activity	Potential prerequisite skills
Listen to music on phone	Turn on phone; locate music app; turn on app; adjust volume; plug in headphones
Play a board game	Roll dice; spin a spinner; count spaces; turn taking; set up the game; learn rules; etc.
Play a card game	Deal cards; hold the cards so other players can't see them; shuffle the deck; etc.
Accessing activities in other environments (i.e., how to get to off-site locations)	Use public transport; request a ride in advance; crossing streets (if walking); using a cab/Uber or other means of transportation, etc.

If a Sampling Leisure Activities objective has been included in the IEP, the sampling period can be used to help identify what types of prerequisite skills may need to be taught.

- Gathering and caring for materials. The individual may need to be taught skills related to any materials or equipment required for an activity. For example, gathering equipment / materials prior to starting the activity; caring for the equipment / materials (e.g., getting uniforms washed, charging electronic devices, washing dishes after a cooking activity, pumping up bike tires, basketball, etc.); putting equipment away when finished, and problem solving (e.g., what to do if materials are missing, broken, or need to be replenished).

- Time management. Time management skills, such as identifying when it is time to engage in a leisure activity, selecting an activity that fits the amount of time for leisure, identifying when activities are available (and tolerating denial or delay of preferred activities), are essential components of increasing independence, access and engagement with leisure activities. Using schedules and calendars can be helpful to structure and prompt leisure activities but may require specific teaching. For example, using a calendar app on a phone can be very useful, but it may be necessary to start off with teaching the student to respond to an alert to engage in an activity and build up to having them enter information into the calendar.

Final Thoughts

Every individual has different interests, abilities, and obstacles to work through in establishing leisure skills, which means there is no one-size-fits-all answer for how to build a meaningful leisure repertoire. However, building on and expanding from high preference, high availability activities and using evidence-based assessment and teaching strategies to establish independence in leisure activities provides a strong foundation from which to start.

References

Blum-Dimaya, A., Reeve, S. A., Reeve, K. F., & Hoch, H. (2010). Teaching children with autism to play a video game using activity schedules and game-embedded simultaneous video modeling. *Education & Treatment of Children, 33*(3), 351-370.

Carlile, K. A., Reeve, S. A., Reeve, K. F., & DeBar, R. M. (2013). Using activity schedules on the iPod touch to teach leisure skills to children with autism. *Education & Treatment of Children, 36*(2), 33-57.

(Continued on page 26)

(Continued from page 25)

Carr, J. E., Nicolson, A. C., & Higbee, T. S. (2000). Evaluation of a brief multiple-stimulus preference assessment in a naturalistic context. *Journal of Applied Behavior Analysis, 33*(3), 353-357.

Chan, J.M., Lambdin, L., Van Laarhoven, T., & Johnson J.W. (2013). Teaching leisure skills to an adult with developmental disabilities using a video prompting intervention package. *Education and Training in Autism and Developmental Disabilities, 48*(3), 412-420.

Chazin, K. T., & Ledford, J. R. (2016). Free operant observation. In *Evidence-based instructional practices for young children with autism and other disabilities*. Retrieved from http://vkc.mc.vanderbilt.edu/ebip/free-operant

Fisher, W.W., Piazza, C.C., Bowman, L.G., & Amari, A. (1996). Integrating caregiver report with a systematic choice assessment. *American Journal on Mental Retardation, 101*(1), 15-25.

Google Search. https://www.google.com/search?q=define+leisure&ie=utf-8&oe=utf-8&client=firefox-b-1 (accessed February 5, 2017).

Graff, R. B., & Karsten, A. M. (2012). Assessing preferences of individuals with developmental disabilities: A survey of current practices. *Behavior Analysis in Practice, 5*(2), 37–48.

MacDuff, G. S., Krantz, P. J., & McClannahan, L. E. (1993). Teaching children with autism to use photographic activity schedules: Maintenance and generalization of complex response chains. *Journal of Applied Behavior Analysis, 26*(1), 89-97.

Schneiter, R., & Devine, M. A. (2001). Reduction of self-injurious behaviors of an individual with autism: Use of a leisure communication book. *Therapeutic Recreation Journal, 35*(3), 207-219.

Toner, N. (2014). How do you figure out what motivates your students? *Science in Autism Treatment, 11*(1), 12-14.

SOME NOTES OF THANKS

Laura Shay, MEd, SLPA

A gracious thank you to **Dr. Lina Slim-Topdjian of the New Jersey ASHA Chapter** for donating $250 in honor of Tracie Lindblad, MSc, SLP, MEd, BCBA, former ASAT Board member and current member of our Professional Advisory Board. Ms. Lindblad spoke about "Arranging Environmental Contingencies that Address Motivation and Preference Assessments" at last year's NJSHA Interprofessional Autism Conference. Thank you Lina and Tracie for this donation!

The "Make Your Mark on Autism" activity where students and staff decorated a puzzle piece to represent themselves in a larger display to show that "Everyone Fits."

We also want to express our gratitude to **Germaine Ibrahim and the Introduction of Applied Behavior Analysis students of Calvary Christian High School, in Old Bridge, New Jersey**. These incredible students spearheaded the first annual Autism Awareness Week and raised funds on two of the five days by hosting a bake sale and a "Dress down in blue" day. Donations were also collected throughout the week. They considered organizations whose mission was committed to validated treatments, dedicated to informing and supporting families, and coming alongside them to offer hope for the future. We are grateful to the students for not only choosing ASAT, but for being a part of a broader movement to promote science-based approaches and quality resources for the autism community.

OUR REAL SCIENCE, REAL HOPE

PROFESSIONAL SPONSORSHIP INITIATIVE

Does Your Agency Share ASAT's Values?

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

We believe that it should not be so challenging for families to find accurate information about the efficacy of various autism interventions. ASAT works toward a time when:

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

What It Means to Be a Sponsor:

ASAT's Sponsors indicate their support of the following tenets:

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

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