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Q&A Summary:
Autism Spectrum Disorder (ASD) Part IV: Treatment Strategies
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1. Can you provide information on N-acetylcysteine (NAC), GABA and addressing zinc to copper ratios?
    a. Please refer to the following articles:
        i. Harden AY, Fung LK, Libove RA, et al. A randomized controlled pilot trial of oral N-acetylcysteine in children with autism*. Biol Psychiatry.* 2012;71:956-61. https://www.ncbi.nlm.nih.gov/pubmed/22342106?dopt=Abstract
        ii. Wink LK, Adams R, Wang Z, et al. A randomized placebo-controlled pilot study of N-acetylcysteine in youth with autism spectrum disorder. *Molecular Autism Brain, Cognition and Behavior*. 2016;7:26 https://molecularautism.biomedcentral.com/articles/10.1186/s13229-016-0088-6
        iii. https://www.autismspeaks.org/science/grants/gabaergic-dysfunction-autism
        iv. https://nccih.nih.gov/news/events/IMlectures/gut-brain
        v. https://www.autismspeaks.org/science/science-news/kids-autism-supplements-often-result-nutrient-imbalances
2. Do you know what particular psychiatric medications help individuals with both autism spectrum disorder (ASD) and fetal alcohol syndrome (FAS) and/or traumatic brain injury (TBI)? I have had children with these comorbid conditions and no medication seems to help control behavioral issues, even if the children are receiving applied behavioral analysis (ABA) therapies full time.
    a. Treatment planning would need to be done on a very individualized basis, combining psychopharmacology and behavioral therapy, as well as other counseling and school and social supports. When treating people with ASD with comorbidities, it is always recommended to start low and go slow. When treating individuals of any age, I try to avoid polypharmacy (though I know that it may be necessary for some people). Depending on age and cognitive level, mindfulness training and cognitive behavioral therapy may be helpful. People with FAS and TBI often need a significant amount of structure in their days to decrease disruptive behaviors. It is always important to make sure that the individual is getting adequate amounts of good quality sleep each night. Looking for other physical ailments is always necessary.

3. Is there any research regarding Parent-Child Interaction Therapy (PCIT) and children with ASD?
    a. The Autism Speaks website reported on this grant:
        i. https://www.autismspeaks.org/science/grants/efficacy-parent-child-interaction-therapy-asd
    b. Please refer to this article published in *Journal of Autism and Developmental Disorders* in 2008:
        i. http://pcitinstituteofsocal.com/wp-content/uploads/2011/03/PCIT-AUTISM.pdf
4. How might we use telehealth and an ABA program together, if ABA clinics in Indiana cannot do in-home treatment?
    a. If telehealth has parity in your state, meaning that insurance would pay equally for telehealth visits as they would for an in-person visit, then you may consider using telehealth for direct ABA supervision and ABA training. Some of the commercial programs even do direct ABA therapy via telehealth (eg, C-serv). Your telehealth service provider, of course, would need to be Health Insurance Portability and Accountability Act (HIPAA) compliant.
    b. This is often directed by funder requirements, so you will want to check there first. Programs such Cserv or Behavior Imaging are available, and some private insurance carriers do cover the services.
    c. Families can also participate in other telehealth initiatives like CARDs remote consultation services or Autism Services North.
    d. At a minimum, families can enroll in trainings through programs such as those offered by Rethink Autism, Relias or Autism Internet Modules.
5. Our local ABA clinics do not do any training or observation in the home with the parents, so the effectiveness of the ABA seems to be greatly affected. I hear that Indiana's insurance does not cover their in-home care. Do you know if this is true, and/or why the clinics may not be doing this in-home service?
    a. Indiana was one of the first states to establish autism reform for commercial carriers for ABA coverage (2001). You can read about that here. Indiana's Medicaid Program added coverage of ABA in 2016 as well, and you can read more about that here.
6. Is there a list of providers of these interventions for every major urban area? Parents (and providers) have incredible difficulties finding appropriate services.
    a. See the Autism Speaks resource guide: https://www.autismspeaks.org/family-services/resource-guide
7. If a child has drawings or printouts all over their bedroom, it appears traumatic to take them down. How should this be handled with a teen with ASD?
    a. Cognitive behavioral therapy could address this issue.
8. Do you have any outcome data on the use of ABA therapy for children with Down syndrome?
    a. Please tune in for *Autism Spectrum Disorder Part V: Dual Diagnosis of Down Syndrome and ASD*, on Tuesday, October 2, 2018 from 1–2 p.m. EST (12–1 p.m. CST). Register at: optumhealtheducation.com/autism-part-V-2018-reg

9. Are there any evidenced-based interventions for adults?
    a. ABA is proven to increase adaptive behaviors and decrease challenging behaviors. Mindfulness training has been found effective to help reduce anxiety and depression in adults with ASD. The mental health and physical health comorbidities need to be treated as well.
10. Please comment on health plans and covered services for ASD.
    a. Please see this link for state autism insurance reform laws: https://www.autismspeaks.org/advocacy/insurance/faqs-state-autism-insurance-reform-laws
    b. Private health insurance plans vary, depending on whether or not it is a "fully insured" plan, a "self-insured" plan or an individual plan. If it is a "fully insured" plan, the health insurance company has taken on the full risk of insuring the members. Then, the decision about ABA coverage goes to the insurance policy and the state mandate. If it is a "self-insured" plan, that means that the health insurance company is the administrator of the plan, but the employer has taken on the risk of paying for the healthcare and the decision about ABA coverage is up to the employer. Self-funded plans are not subject to state mandate. If it is a private policy, then it depends on what the individual purchaser decided to buy.
11. You mentioned that a child with autism is under the school system until age 22. Is that mandated? If so, where can I find it? Our school basically has said they have done all they can do and is graduating one of the children at my center at age 18. He cannot attend the 18+ program.
    a. Any child who has an IEP and who still meets IEP eligibility is eligible for services until their 22nd birthday.
    b. Here are some websites for further information and/or help with advocacy:
        i. https://www.parentcenterhub.org/
        ii. http://www.wrightslaw.com/info/trans.index.htm
        iii. From OSERS (Office of Special Education and Resource Services), a transition guide - https://sites.ed.gov/idea/files/postsecondary-transition-guide-may-2017.pdf
        iv. Autism Speaks toolkits: https://www.autismspeaks.org/family-services/tool-kits/iep-guide, https://www.autismspeaks.org/family-services/tool-kits/transition-tool-kit
12. How would a family with a child diagnosed with ASD, obsessive-compulsive disorder (OCD), attention deficit disorder (ADD), attention deficit hyperactivity disorder (ADHD), and Tourette syndrome determine if the child should be on disability or supplemental insurance to get the most benefits?
    a. I think that it would be worth consulting with a disability attorney. Some employers have employee assistance programs (EAPs) that can provide legal consultations for free.
    b. There is also helpful information on these websites:
        i. https://www.autismspeaks.org/family-services/tool-kits/financial-planning
        ii. https://faq.ssa.gov/en-US/topic/?id=CAT-01094

13. Is there help for high-functioning adults who never matured to living independently and received no help as a child?
    a. I would look into your state Developmental Disabilities Council, your local autism agencies and your state Autism Speaks organization.
    b. See the Autism Speaks resource guide: https://www.autismspeaks.org/family-services/resource-guide
14. What is more effective for children with ASD: mainstreamed in the public school system or enrolled in a private school for children with multiple special needs? Academically and socially speaking?
    a. This really depends on so many things: the individual child's strengths and needs, other outside activities, level of communication and cognition, individual school system and other outside therapies, to name a few. I cannot give a specific answer without knowing the child, the family and the community.
15. I would like any research or links on possible relationships between ASD and food allergies along with treatment options.
    a. Children with autism can have any other health problem, just like children without autism. There is not a reported, scientifically proven "link" between food allergies and autism. A true food allergy is often determined by positive testing on both blood and skin prick tests. These tests are often managed by allergists and gastroenterologists.
16. Is ABA used and/or covered for other types of diagnoses, not just ASD?
    a. Used, yes. There are no restrictions on diagnosis or age when it comes to the effectiveness of ABA. Research beyond autism is available, but less prevalent, possibly due to funding limitations.
    b. Most health plans are not required to cover ABA services outside of ASD, and as such, many will not. It is, however, plan specific since some health plans will cover the services regardless of the diagnosis coding.
17. Is ABA appropriate for high-functioning children with ASD who also have ADD and OCD?
    a. Yes. Often, focused ABA is used to treat individuals who have precise behavioral challenges that limit or interfere with their ability to learn in the natural environment. This can include ADD and OCD.
18. Is ABA still effective for college-aged students?
    a. Yes, ABA is focused on behavior and its functional relationship within the environment. Therefore, its utilization and effectiveness are not restricted by age or diagnosis.
    b. Funders may have restrictions based on their individualized criteria and guidelines for medical necessity. However, many of the insurance mandates were designed to cover individuals up to the age of 26 years.
19. What is the average amount of time that an ABA therapist works with a child and family?
    a. This is dependent on the individual needs of each child and family. In general, ABA research supports the effectiveness of comprehensive ABA in children under the age of 7 as being 25 to 40 hours per week, 52 weeks per year, for a period of 2 to 3 years.

b. Focused treatment is often provided in the dosage of 10 to 20 hours per week, and while intended to be shorter in term (if effective, the need for long-term services would not be necessary), treatment can be extended depending on the needs of the individual.

20. Do you believe in-home, clinic or school-based therapy is more effective with ABA therapy?
    a. This is truly dependent on the individual needs of the child and the family. Because ABA relies heavily on the interaction of behavior and its environment, treatment across multiple environments is of importance, especially in comprehensive ABA programs. Both clinic-based and home-based models have their advantages and disadvantages. The model often used in research is to begin with clinic-based care (as you have more consistent ability to contrive settings and control environmental barriers) and then transition to the home and community as the child is successful and/or has the specific skill sets necessary to be successful in the home environment. Some families are able and willing to allow for an environment with very few interruptions that allows for a contrived/controlled treatment setting; when this is a possibility, the need for clinic-based care may be specific to other considerations such as the individual's need to target transitions, transportation or social skills. Treatment solely provided in the center and never transitioned or carried out in the home environment would be less favorable as the skills taught in one environment may not automatically generalize to another environment.
    b. In a focused ABA program, the targeted behavior may only occur in a specific environment. However, using the environment in which the behavior does not occur is still beneficial for assessment purposes (ie, what does work in the environment absent of the concern) as well as to teach skills necessary to prepare the learner for success when treatment is provided in the specific environment where the behavior occurs (ie, alternative behaviors, coping strategies, etc.).
21. Any known research on ABA effectiveness with families whose primary language is not English?
    a. ABA's effectiveness is not restricted to English-language users. In fact, behavior analysts are located all over the world, and the certification process for a behavior analyst’s native language is translated (specifically, the certification exam) into nine different languages with four additional exam versions currently in the process of being translated.
    b. The key to its effectiveness is having a provider who is familiar with the variations in cultural considerations and fluent in the primary language of the family. Some providers will use translation services due to limited accessibility of services provided in a family’s primary language. However, this is not always preferred, as the board-certified behavior analyst (BCBA) supervisor’s ability to train the parents/caregiver effectively to monitor the fidelity of treatment implementation is limited. Therefore, it is best that the family, where and when available, receive services from a behavior analyst who speaks the family's primary language. This

should not be a reason why a family should not have access to services though, since there are translation services available for support.

22. What resources are becoming available for parents with autistic children who speak another language than English? Any technical resources available when the ABA trainers only speak English?
    a. There is an increasing demand for bilingual (Spanish speaking, primarily, but other languages as well) services in the autism community. Due to the vast growth of professional behavior analysts, many organizations are able to expand their practice to include services in Spanish. Due to the high demand, many trainings, webinars, parent tool kits, etc. are translated into Spanish as well. I am aware of several BCBAs who are bilingual in other languages who do have a vast interest in expanding the resources available to underserved populations (such as those who do not primarily speak English); however, the resource base is very limited.
    b. Autism Speaks has created a 100-Day Toolkit that provides families of children under age four information about what to do in the first 100 days after an autism diagnosis. This kit includes information about autism, services, treatment, useful forms and a glossary of terms. This kit is free and has been translated into several languages. It can be accessed at https://www.autismspeaks.org/family-services/non-english-resources.
23. Is there any research with ABA and Angelman Syndrome?
    a. Research specific to ABA and treatment of specific genetic disorders is limited. There is a single study completed by Dr Jane Summers (2012) published in the *Journal of Developmental Neurorehabilitation*.
    b. I think the key thing to keep in mind is that while ABA may not be considered a "treatment" for Angelman syndrome directly, the characteristics associated with Angelman syndrome include specific behavioral traits that can be improved through the use of ABA, as is done with ASD.
24. What is the best way to handle repetitive topics?
    a. We often will teach portions of the Social Thinking curriculum that talk about a Social Filter. This teaches children how to deal with understanding when an appropriate time to talk about repetitive topics is and when they should "filter" themselves and use another topic. We have also been successful with visuals (i.e., a stop sign to be held up in treatment when the child is re-using a topic) or a simple phrase (i.e., "Next topic" or "We already have spoken about that").

If you have questions regarding this document or the content herein, please contact: moreinfo@optumhealtheducation.com.