



Q&A Summary: Autism Spectrum Disorder (ASD) Part I: Overview, Screening, Diagnosis and Treatment Planning

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- 1. What was autism identified as 100 years ago? It seems such a new disorder, I wonder if it's environmental.
 - a. Autism was first described by Dr. Leo Kanner, an Austrian-American psychiatrist, in 1943. He reported on 11 children who "exhibited an apparently congenital lack of interest in other people." More information is available on the Autism Speaks website, citing a *New England Journal of Medicine* article that was published in 2013: <u>https://www.autismspeaks.org/science/science-news/autism-70-%e2%80%93-kanner-dsm-5</u>
- 2. Can you review the prenatal risks again please?
 - a. The prenatal risks that I discussed are likely associations and include prematurity, low birth weight, intrapartum hypoxia (loss of oxygen), in utero alcohol exposure, maternal use of valproate (a seizure medication) and infections (rubella and cytomegalovirus). These are just a few examples.
- 3. Do you see a higher risk in children with parents who have psychiatric diagnosis?
 - a. This will be addressed during Part III of our webcast series on ASD and genetics. The live webcast will be on August 7, 2018 and it will be made available ondemand on or around August 14, 2018. More information can be found on: <u>https://www.optumhealtheducation.com</u>
- 4. I believe I heard you say there is a higher prevalence of ASD in higher socioeconomic status. Is that correct? If so, can you explain why that is?
 - a. It is likely that children living in higher socioeconomic status communities have greater access to screening and diagnosis. Please note that I said, "It is likely."
- 5. Is the prevalence of white male diagnosis higher due to lack of proper medical diagnosis by other ethnicities?
 - a. It is true that, historically, other ethnic communities have had less access to screening and diagnosis. Many experts have stated that the increased prevalence in the most recent Centers for Disease Control (CDC) data that I discussed is, in part, likely due to increased rate of screening and diagnosis in Hispanic and African-American communities. Please see the Autism Speaks website for more information: https://www.autismspeaks.org/science/science-news/cdc-increases-estimate-autism%E2%80%99s-prevalence-15-percent-1-59-children
- 6. Is there any recent research supporting evidence for the "reasons" for the increased incidence of autism?
 - a. Please see #5. A lot of research being done today is being done to determine the etiology (cause) of autism. Most of the research is pointing to genetic causes.

- 7. Do we have a set time frame in which doctors should be screening?
 - a. Yes, pediatric primary care providers (PCPs) should be screening for autism at the 18-month and 24-month well-child visits, as recommended by the American Academy of Pediatricians (AAP) and the CDC, or when a parent /caregiver or PCP has concerns.
 - i. <u>https://www.aap.org/en-us/professional-resources/quality-improvement/Quality-Improvement-Innovation-Networks/Documents/Autism_PreSIP.pdf</u>
 - ii. https://www.aap.org/en-us/about-the-aap/Committees-Councils-Sections/Council-on-Children-with-Disabilities/Pages/Autism.aspx
 - iii. https://www.cdc.gov/ncbddd/autism/hcp-recommendations.html
- 8. Should you do both an 18-month Ages and Stages Questionnaire (ASQ) and an 18month Modified Checklist for Autism in Toddlers, Revised (MCHAT-R)?
 - a. Yes, the ASQ is an overall developmental screening tool, looking at cognitive, motor, language and social-emotional development, while the MCHAT-R is a specific autism screening tool.
- 9. Is it reasonable to suggest an ASD screening if a child has another diagnosed condition and the common interventions are not effective when the child has symptoms that cross over with ASD criteria, to rule it out if nothing else?
 - a. It is always reasonable to do an ASD screen if there are concerns.
- 10. Can a diagnosis be "missed" during childhood and then realized in someone's early 20s?
 - a. Yes, especially in people who have average to above average intelligence (IQ).
- 11. Can ASD be compounded by or confused with other disorders such as mixed expressive-receptive language disorder?
 - a. Children with ASD have language delays /disorders, so they may also be diagnosed with mixed expressive-receptive language disorder.
- 12. Can autism be missed as a child and diagnosed as a teenager?
 - a. Yes. See #10.
- 13. How commonly is ASD diagnosed as attention deficit hyperactivity disorder (ADHD)?
 - a. I do not know this answer. However, people with ASD may also have ADHD. People with ADHD and language disorders sometimes screen as positive for ASD, but with further evaluation may not meet the full criteria for ASD.
- 14. Do you think it is possible that an adult could have high functioning autism but was never diagnosed?
 - a. Yes. See #10.
- 15. If a child has not spoken at 24 months, does that mean he or she has autism?
 - a. No, that means that the child has significant language delays and needs further evaluation for the reason for his/her language delays. That evaluation must include a hearing test, an evaluation by a speech/language pathologist (therapist) and evaluation for autism and other disorders, if the child has normal hearing.
- 16. If a school refuses to test for autism based on the fact that a definite diagnosis would not change the way that the child would be taught, is there any recourse?
 - a. This is a difficult question. If the child is successful in school, then the school may say that there is no reason to test. An individualized education program (IEP) is provided when a child requires special education services to be educated. If there is concern that the child has autism, but it is not affecting his school work, then the parent will likely need to get an outside evaluation. If the child is diagnosed with autism and the parent thinks that the child would benefit from school accommodations, then the child may be eligible for a 504 plan, but that falls under regular education services, not special education services.

- 17. If the child receives early intervention and their skills get better, and the issues become more minimal, do they still retain the diagnosis? Can someone grow out of the diagnosis?
 - a. This is controversial. There are certainly some children who benefit greatly from early intervention and may not need therapies /services subsequently. However, I would suggest continued monitoring as the social challenges increase with age.
- 18. Is it common for babies to start talking at 9-12 months and just stop talking at about 18 months?
 - a. It is not common, but there are approximately 20% to 25% of children with ASD who have the "regressive" form of ASD. These children often lose language and social skills around 18-24 months of age. Other evaluations are especially necessary for these children, including a hearing test, considering an evaluation with an electroencephalogram (EEG) for seizure disorder, metabolic testing, etc.
- 19. Since the *Diagnostic and Statistical Manual of Mental Disorders*, 5th edition (DSM-5), my son—who was originally diagnosed in 1993 with (high functioning) ASD (not Asperger's)—now meets the criteria for significant ADHD. As a medical professional, would you use only the ADHD diagnosis, even if he still exhibits symptoms of ASD?
 - a. No. A person can be diagnosed with both ASD and ADHD.
- 20. Do you think that many children are not diagnosed correctly with attention deficit disorder (ADD) and are really on the spectrum?
 - a. I think that it is possible for a child to be misdiagnosed with ADHD instead of ASD and vice versa. A comprehensive evaluation is always important to determine the correct diagnosis.
- 21. What about children who may have ASD but are much older than 3 years?
 - a. Children at any age with concerns for ASD should have an evaluation.
- 22. What are the early signs of autism?
 - a. Delays in social and language skills (no babbling by 12 months; lack of responsive smiles; poor eye contact; no back and forth gestures; no words by 16 months; and any loss of speech, babbling or social skills). Please see the following websites for further information:
 - i. https://www.autismspeaks.org/what-autism/learn-signs
 - ii. https://www.cdc.gov/ncbddd/autism/signs.html
 - iii. https://www.cdc.gov/ncbddd/actearly/index.html
- 23. For the child himself that recognizes he is different in some way from his peers, does the diagnosis of ASD give him some relief?
 - a. Yes, it certainly can. There are some great videos and books out there that can help people with ASD understand that they are not alone.
- 24. Parents often state that their child was "normal" and suddenly developed autism at 6-9 years old. Your comment?
 - a. That is unlikely. Children may seem normal and then have regression between 18-24 months of age. If a child regresses at 6-9 years old, then further evaluation for other conditions needs to be done.
- 25. Is there any possibility of diagnosis occurring earlier than at age 3?
 - a. Yes. Parents often have concerns before 2 years of age and diagnosis can be accurate at earlier than 3 years old.
- 26. Can autism be inherited from a parent with ASD?
 - a. Yes, it is possible, as many children (up to 20%-25%) can be found to have a genetic mutation associated with their ASD. This will also be addressed during Part III of our webcast series on ASD and genetics. The live webcast will be on August 7, 2018 and it will be made available on-demand on or around August 14, 2018. More information can be found on: <u>https://www.optumhealtheducation.com</u>

- 27. I have 2 nephews (brothers) who are 11 months apart and both are children with autism. How common is that?
 - a. Since we know that many children with ASD are now found to have a genetic reason for their ASD, it is likely that these 2 boys have a genetic mutation contributing to their ASD.
- 28. Where can I find more information on fragile X syndrome?
 - a. The National Fragile X Foundation https://fragilex.org/
- 29. Can you speak to some of the differences in autism vs Fetal Alcohol Spectrum disorders (FASD)?
 - a. There are differences and similarities. Some children with FASD may be diagnosed with ASD. Simplistically, those children with ASD have social and language skills that are more delayed than their other developmental areas and they have more ritualistic and repetitive behaviors. However, others will state that there are differences: <u>https://www.nofas.org/faqs/what-is-the-difference-between-fasd-and-autism-spectrum-disorder-asd/</u>
 - b. For more information on FASD, please see the National Organization on Fetal Alcohol syndrome: <u>https://www.nofas.org</u>
- 30. Can you talk a little about the similarities and differences in ASD and ADHD?
 - a. People with ASD may also have ADHD. People with ADHD and language disorders sometimes screen positive for ASD, but with further evaluation may not meet the full criteria for ASD.
- 31. How can you distinguish symptoms of ASD vs normal childhood or toddler behavior at an early age?
 - a. Children with ASD have impairments in social communication /language and also have repetitive, restrictive, ritualistic behaviors, interests or activities.
- 32. How would you determine the difference between a child with severe language impairment and autism (especially if the child is engaging, has good eye contact, and is loving and social)?
 - a. If a child with severe language impairment has great social skills, then it is unlikely that he/she has autism.
- 33. Can you talk about how to distinguish between ASD and obsessive-compulsive disorder (OCD)?
 - a. Children with autism have repetitive, restrictive, ritualistic behaviors, interests or activities, as part of the diagnosis. Children with OCD and not ASD should have normal social communication skills.
 - b. Please see the American Academy of Child and Adolescent Psychiatry for further information. <u>https://www.aacap.org/AACAP/Families_and_Youth/Facts_for_Families/FFF-Guide/Obsessive-Compulsive-Disorder-In-Children-And-Adolescents-060.aspx</u>
- 34. For a child under age 3 to have OCD-like tendencies but no other overt signs of autism, should autism still be considered?
 - a. Yes. It would be helpful for the child to have a full evaluation.
- 35. Are neurocognitive abnormalities known to be associated with neonatal open heart surgery? Is ASD a known association? I have a few.
 - We know that children with congenital heart disease are at higher risk for neurodevelopmental disabilities.
 Here is an article from Yale News: <u>https://news.yale.edu/2017/10/09/congenitalheart-disease-genes-linked-autism-and-other-disorders</u>
 It was published in Nature: https://www.nature.com/articles/ng.3970
- 36. Is hyperlexia seen in high functioning children with autism?
 - a. Sometimes, yes.

- 37. Is there an association with prenatal antidepressant use and ASD?
 - There are published articles that cite this as a possible contributing factor. Please see this *British Medical Journal* article: https://www.bmj.com/content/358/bmj.j3388
- 38. How to best evaluate adults for autism?
 - a. An adult psychiatrist or psychologist can do this evaluation. I would first ask the professional about their experience in adults with autism.
- 39. Is there any correlation with an increase in behaviors and puberty? Especially in boys?
 - a. Yes, with puberty come hormone changes and with hormone changes come behavioral changes. Teenagers with autism have the same hormone changes as teenagers without autism.
- 40. Why is autism more prevalent in boys vs girls?
 - a. That is still being studied.
- 41. A research study indicates the there is a higher risk of ASD with deliveries that were induced with pitocin. What is the current view related to this study? "Increased Risk of Autism Development in Children Whose Mothers Experienced Birth Complications or Received Labor and Delivery Drugs" *ASN Neuro*. 2016 Jul-Aug; 8(4): 1759091416659742.
 - a. I think that more research is needed in this area. This study you cited is a small study with 49 children with an ASD diagnosis and 104 children without ASD. This report below reports no increased risk of autism with use of pitocin: <u>https://www.autismspeaks.org/science/science-news/reassuring-findings-large-study-induced-labor-and-autism-risk</u>
 - b. https://www.autismspeaks.org/blog/2012/06/01/autism-pitocin-connection
- 42. Can autism affect life expectancy?
 - a. Mortality rate is likely increased in persons with ASD and epilepsy: <u>https://www.autismspeaks.org/about-us/press-releases/mortality-rate-increased-persons-autism-who-also-have-epilepsy</u>
 - b. And it is possible that it is increased in people with autism overall, but more research is needed in this area: <u>https://www.autismspeaks.org/science/science-news/mortality-and-cause-death</u>
 - c. People do not die from autism, but people with autism are at higher risk of drowning and other accidents:
 - i. http://nationalautismassociation.org/resources/autism-fact-sheet/
 - ii. https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2017.303696
- 43. I am working with a mother who has Asperger's Syndrome. Her infant has complex medical needs. Our communication is 100% telephonic. Can you recommend any strategies that may work best for this type of communication to best address the family's and infant's needs?
 - a. I would suggest asking the mother and the family how she/they best understand information and provide information. It may be in writing or talking or both. I would also suggest using a "teach back" method, meaning that you request that the person tell you what they understood you to say. You may find this website helpful: <u>https://www.ahrq.gov/professionals/quality-patient-safety/quality-resources/tools/literacy-toolkit/healthlittoolkit2-tool5.html</u>

- 44. Could you discuss a bit more about differential interventions/assessments for children with comorbidities? A child with autism and vision loss, a child with autism and deafness, a child with autism and physical disabilities, etc.
 - a. Children with ASD and other comorbidities require the same treatment for ASD, but it may need to be modified due to their other sensory or physical impairments.
 - b. The comorbidities need to be treated as well, of course.
- 45. I know you will talk about the dual diagnosis during Part VI of the series, but I want to ask you today: Is autism usually accompanied with other syndromes such as Savant Syndrome?
 - a. Most people with autism do not also have "Savant Syndrome." Savant syndrome is not a DSM diagnosis.
 - b. For further information, I refer you to:
 - i. <u>https://www.wisconsinmedicalsociety.org/professional/savant-</u> syndrome/savant-syndrome-overview/
- 46. Are "tics" seen as a "repetitive behavior" in high functioning children with autism (i.e., mouth noises, breathing, chewing on a fingernail)?
 - a. A tic is an involuntary repetitive motor movement. A repetitive behavior in a child with autism is a voluntary behavior that is often self-soothing.
 - i. For further information about Tic Disorders: <u>https://www.aacap.org/AACAP/Families and Youth/Facts for</u> <u>Families/FFF-Guide/Tic-Disorders-035.aspx</u>
 - ii. https://www.cdc.gov/ncbddd/tourette/diagnosis.html
 - iii. https://www.tourette.org/about-tourette/overview/what-is-tourette/
- 47. Is sensory integration therapy effective?
 - a. Evidence is increasing that sensory integration therapy can be effective for children with sensory processing problems, but more work needs to be done in this field. Please see the Autism Speaks website for more information: <u>https://www.autismspeaks.org/science/science-news/study-finds-sensory-integration-therapy-benefits-children-autism</u>
- 48. What about children who become violent if screen time is taken away?
 - a. I would recommend working with the child's applied behavioral analysis (ABA) or behavioral therapist on this. There are many strategies to use, such as using a written or picture schedule, using a timer and using screen time as the reward. This means that the child must finish all chores, homework, etc. prior to given screen time.
- 49. What is the best source to find top rated schools for children with ASD?
 - a. I would inquire at your state department of education.
 - b. Autism Speaks has a resource guide: <u>https://www.autismspeaks.org/family-</u> services/resource-guide
 - c. The Autism Society resource guide may also be helpful: <u>http://www.autismsource.org/</u>
- 50. What is the link, if any, with food sensitivities? I cared for an autistic, nonverbal boy who would be having a great day, and as soon as he ate lunch would get very aggressive, have increased repetitive motions and pass a lot of gas. Would this have any connection, or would it just be considered part of his dietary restrictions?
 - a. Some children with and without autism may have food sensitivities or food allergies. If a child has gastrointestinal symptoms, I would always recommend a gastroenterology evaluation.

- 51. When a child is getting ABA services, it sometimes is difficult to distinguish the treatment goals for ASD from typical developmental milestones. Any comment?
 - a. I am not sure what this question is asking. Our goal for therapy is for the child to gain skills towards typical development.
- 52. With therapy and early intervention, can children with ASD fully integrate, or will they always have disabilities?
 - a. Those are 2 separate ideas. One of our goals of therapy /intervention is for the child with ASD to be able to integrate with typical peers and have improved adaptive behavior /skills, as well as improved social communication and fewer impairments overall. A disability is a physical or mental condition that limits a person's movements, senses or activities; it is a disadvantage, a handicap. We hope that interventions decrease the person's disability.
- 53. Would excessive use of videogames be considered repetitive use of objects?
- a. Excessive use of video games is not only a problem for children with autism. 54. Would psych medications be a factor?
 - a. I am not sure what this is asking. Some children with ASD need psychopharmacology (psychiatric medication), as part of their treatment regimen.
- 55. You mentioned referral to occupational therapy (OT) for sensory issues, but right now United Healthcare (UHC) does not cover "sensory integration" as there is not enough research to support it. It is considered "experimental and investigational". Is someone doing ongoing research to see if more studies have been to support this? Parents need to turn to someone for at least instruction in home exercises.
 - a. Yes, that is true. There is not enough evidence-based information for insurance companies to pay for sensory integration therapy. There is research being done. Often, the child with ASD also has fine motor coordination disorder, fine motor delays or self-help delays that do warrant medically necessary occupational therapy. If the child's sensory processing problems are negatively impacting their self-help skills or other areas, then the OT can address these. Also, in school, the OT can provide the child with a "sensory diet," if needed, and parents can adapt this in the home.
- 56. When to work on weaning children/teens off medications?
 - a. That decision is between the parent, the teen and the medical prescriber.
- 57. Do children getting ABA services run the risk of regression if treatment is stopped? Or is it more often the case that they just do not progress without continued treatment?
 - a. This would require more discussion. Briefly, ABA should be implemented throughout the child's day, not just by the therapist. Children with ASD should also be in school, receiving special education as needed, as well as other therapies such as speech /language therapy.
- 58. Constipation/limited eating is so prevalent in children with autism. Any specific treatments for the comorbidity of constipation and bowel toilet training?
 - a. We will be further discussing medical home care in the Part 2 webinar.
 - b. Please work with the child's pediatric primary care provider and /or gastroenterologist and /or dietitian (nutritionist) on diet and constipation.
 - c. An ABA therapist and /or a feeding therapist can work on eating as well.
 - d. Autism Speaks has a toolkit on constipation: <u>https://www.autismspeaks.org/science/find-resources-</u> programs/autism-treatment-network/tools-you-can-use/atn-air-p-guide-managingconstipation-children
 - e. Autism Speaks has a toolkit on Feeding Behaviors: <u>https://www.autismspeaks.org/science/find-resources-</u>

programs/autism-treatment-network/tools-you-can-use/atn-air-p-guide-exploring-feeding-behavior

- f. For further information about toileting, please see the Autism Speaks Toolkit: <u>https://www.autismspeaks.org/science/resources-programs/autism-treatment-network/atn-air-p-toilet-training</u>
- 59. Is there a link between immunizations and ASD?
 - a. Immunizations do NOT cause ASD.
 - i. <u>https://www.autismspeaks.org/science/science-news/new-meta-analysis-</u>confirms-no-association-between-vaccines-and-autism
 - ii. https://www.cdc.gov/vaccinesafety/concerns/autism.html
- 60. Is autism a genetic disorder or is it linked to the measles, mumps, and rubella (MMR) Vaccine?
 - a. MMR does not cause autism.
 - i. <u>https://www.autismspeaks.org/science/science-news/no-mmr-autism-link-large-study-vaccinated-vs-unvaccinated-kids</u>
- 61. Do you know why no New England states were included in the study of prevalence?
 - a. I do not know how the states were picked. However, here is the recent article: https://www.cdc.gov/mmwr/volumes/67/ss/ss6706a1.htm
 - b. The CDC also has more information about prevalence: <u>https://www.cdc.gov/ncbddd/autism/data.html</u>
- 62. I heard on the news in New Jersey over the weekend that the reason they feel there is an increase in diagnoses of autism is because the state provides autism screening tools more than other states (they are more adept at screening for autism).
 - a. Yes, that has been reported.
- 63. Can child developmental centers bill for developmental screenings or is this just for pediatricians?
 - a. Any medical provider can bill for developmental screening using code 96110.
- 64. Can 96110 be billed along with the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) screening code?
 - a. Yes. Please talk to your state Medicaid, as there may be different modifiers to add on.
- 65. Are their only certain providers that can bill the 96110?
 - a. 96110 is a billing code for medical providers to use.
- 66. Are these screenings covered by insurance at each age?
 - a. That is dependent on the insurance and the state.

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