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AUTISM
5 misconceptions that can complicate care

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Despite an increasing understanding of autism spectrum disorder, misinformation abounds. Here's help dispelling common misconceptions.

PRACTICE RECOMMENDATIONS

› *Screen children for developmental delays with a standardized screening tool at 9, 18, and 24 or 30 months of age, accompanied by surveillance at all well-child visits.* (C)

› *Use a parent-completed tool rather than a directly administered tool to screen for developmental delays.* (C)

› *Advise parents of a child diagnosed with autism spectrum disorder that early intensive behavioral therapy can improve cognitive, language, and adaptive skills..* (A)

Strength of recommendation (SOR)

(A) Good-quality patient-oriented evidence
(B) Inconsistent or limited-quality patient-oriented evidence
(C) Consensus, usual practice, opinion, disease-oriented evidence, case series

Autism spectrum disorder (ASD) affects approximately one in 68 children in the United States, according to the Centers for Disease Control and Prevention (CDC).[1] Growing public awareness of autism means that family physicians are increasingly likely to hear from anxious new (and expectant) parents.

Unfortunately, misinformation about autism continues to be perpetuated, through word of mouth, the Internet, and misinformed advocacy groups. This article addresses 5 of the most common misconceptions, and can help you set the record straight and respond appropriately to parental concerns.

MISCONCEPTION 1: Autism is a single condition

While autistic disorder was previously considered one of 5 pervasive developmental disorders, in 2013 the *Diagnostic and Statistical Manual of Mental Disorder, 5th edition* (*DSM-5*) redefined it. (To learn more about how shifts in our understanding of autism were reflected in each new edition of the *DSM*, see "Autism: Why the rise in rates?" on page 316.)

ASD is now an umbrella term that encompasses autism, Asperger syndrome, pervasive developmental disorder not otherwise specified, childhood disintegrative disorder, and Rett syndrome.[2] The new term is meant to highlight the continuum of symptoms and frequent variability of presentation among those affected, ranging from mild to more severe impairment. Anyone who was classified under *DSM-IV* criteria, of course, should continue to have an autism/ASD diagnosis.

As with previous definitions, ASD is characterized by communication deficits (eg, inappropriate responses in conversation, misinterpreted nonverbal interactions, and significant challenges in age-appropriate bonding/friendship development). While previous definitions were focused on identifying school-age deficits, the update requires early childhood symptoms—regardless of the age of formal diagnosis.[2]

MISCONCEPTION 2: Only symptomatic children should be screened for ASD

Although the decision to screen all children remains a controversial one, at least one medical society—the American Academy of Pediatrics (AAP)—calls for universal screening.[3] The American Academy of Family Physicians does not have or endorse a formal guideline about screening for ASD. The US Preventive Services Task Force has a guideline, but it is in the process of being revised.[4]

Given the advances in early childhood interventions, there is little doubt that early identification of those at risk for developmental delay is beneficial. But opponents of universal screening cite concerns about unnecessary testing, anxiety, and overdiagnosis due to false positives associated with traditional screening methods.

The AAP calls for screening and surveillance. Since 2006, the AAP has recommended surveillance at all well-child visits, combined with screening for developmental delays at 9, 18, and 24 or 30 months of age, using a standardized screening tool.[3,5] A parent-completed tool (eg, the Modified Checklist for Autism in Toddlers [M-CHAT] or, most recently, the M-CHAT Revised with Follow-up[6]; Parents' Evaluation of Developmental Status; or Ages and Stages Questionnaire, 3rd ed) should be used rather than a directly administered tool.[3,5] An algorithm detailing the AAP's approach is available at http://www.cdc.gov/ncbddd/actearly/autism/case-modules/pdf/diagnosis/AAP%20Screening%20Guidelines.pdf.

Physicians should also be prepared to evaluate any child whose parents raise concerns about his or her development during a routine visit. A "wait and see" approach is strongly discouraged. Parents of children with ASD often broach the subject by the baby's first birthday.[5] Common concerns include the child's inability to babble, point or gesture meaningfully, or respond to his or her name; poor eye contact; failure to play with toys; and/or loss of (or failure to develop) language or social skills.[5]

An ASD mnemonic. The CDC, in collaboration with the AAP, the American Academy of Neurology, and the Child Neurology Society, has released a simplified guideline with the mnemonic ALARM to summarize recommendations for developmental screening, surveillance, diagnosis, and management of ASD.[5] ALARM stands for:

- **A**utism is prevalent
- **L**isten to parents
- **A**ct early
- **R**efer
- **M**onitor.

MISCONCEPTION 3: Since ASD can't be cured, early intervention offers no benefit

While there is no cure for ASD and it is not considered reversible, there is an array of potential ASD therapies and proven benefits of early intervention. Therapies range from diet to medication and behavioral skills development, but only a few have ample evidence of efficacy **(TABLE)**.[7-17]

Randomized controlled trials of early developmental and behavioral therapy have shown some promise in decreasing symptoms associated with ASD and improving parent-child communication and social engagement.[18-21] A systematic review found that young children with ASD can improve cognitive performance, language skills, and adaptive behavioral skills through behavioral interventions or more comprehensive approaches using developmental and behavioral frameworks.[22] In addition to increasing the likelihood of overall school success, early intervention programs that improve communication and social skills can have a significant impact on the individual's eventual quality of life (QOL), employability, and independence.[23-25]

CONTINUED

Avoid a "wait and see" approach. Parents of children with ASD often broach the subject by the baby's first birthday.

TABLE

Therapeutic options for ASD: What works?[7-17]

Intervention	Effectiveness (SOR*)
	Effective
Early intensive behavioral therapy[7]	A
Melatonin (for sleep disturbance)[8]	A
Parent-mediated early intervention[9]	A
Risperidone (for behavioral issues)[10]	A
	Inadequate evidence to support
Acetylcholinesterase inhibitors[14]	B
Acupuncture[11]	B
Atypical antipsychotics[12]	B
Auditory integration therapy[13]	A
B6-magnesium supplementation[14]	B
Gluten-free/casein-free diet[15]	A
Music therapy[13]	A
Naltrexone[14]	B
Omega-3 fatty acids[16]	A
	Ineffective
Secretin IV[17]	A

ASD, autism spectrum disorder; IV, intravenous; SOR, strength of recommendation.

*SOR: **A,** Good-quality patient-oriented evidence; **B,** inconsistent or limited-quality patient-oriented evidence; **C,** consensus, usual practice, opinion, disease-oriented evidence, case series.

Patients with ASD are less likely to have ever lived on their own than those with learning disabilities, intellectual disabilities, or emotional disturbances.

MISCONCEPTION 4: Individuals with ASD are intellectually disabled and can't function independently

As many as 96% of children with ASD have a coexisting developmental disability, such as generalized developmental delay (found in 80% of those with ASD), learning disabilities (affecting 60%), or attention-deficit/hyperactivity disorder (in 42%).[26] Although many parents—and some physicians—assume that children with ASD are intellectually disabled, in fact, less than one in 5 (19%) has an intellectual disability.[26]

Individuals with ASD do, however, often have difficulty living independently. In one study of post high school living arrangements, those with ASD were less likely to have ever lived on their own than those with learning disabilities, intellectual disabilities, or emotional disturbances.[23]

Another analysis found that only about half (53.4%) of young adults with ASD had ever worked for pay outside the home since leaving high school—the lowest rate among disability groups.[24] Of those who had worked outside the home, young adults with ASD earned an average of $8.10 per hour, significantly lower than the comparison groups. Not surprisingly, young adults with ASD who had better conversational and/or functional skills had a higher likelihood of ever having had worked for pay outside the home.[24]

Social participation also is considered an indicator of overall QOL and independent function. Young adults with ASD were found to be significantly more likely than those with other types of developmental delays to be socially isolated—never seeing friends, getting calls from friends, or being invited to activities. Lower communication and functional skills, as well as living with a parent, were predictors of less social participation in young adults with ASD.[25]

MISCONCEPTION 5: Thimerosal vaccines cause ASD

The controversy and concern about a correlation between mercury and ASD began in the late 1990s, when a published study appeared to link thimerosal-containing vaccines to the increasing incidence of autism.[27] This notion appeared to be further strengthened by a 2002 study,[28] done by the same researchers and reaching similar conclusions. Since then, the correlation has been disproven by a number of studies and further review of the initial studies revealed them to be flawed.[29]

Despite the lack of evidence to support any long-term effects from the minimal exposure to mercury in the preservative, in July 1999, US Public Health Service agencies, the AAP, and vaccine manufacturers agreed that thimerosal should be reduced or eliminated in vaccines as a precautionary measure.[30] With the exception of a limited number of multidose influenza vaccines, childhood vaccines are now thimerosal-free.

FACT: Early referral is key

When and where to refer parents for additional evaluation of a child with developmental delays depends on the resources in your community. Typically, a team of providers participates in the evaluation and management of a child with ASD, often including a developmental pediatrician, psychiatrist and other mental health professional, neurologist, speech pathologist, audiologist, physical therapist, and special education teacher.

Although every community may not have easy access to a pediatric subspecialist referral center, all 50 states and US territories are required by law to provide access to early intervention programs under Part C of the 2004 Individuals with Disabilities Education Act.[31] (For a list of resources, see "Autism spectrum disorder: Where to learn more" on page 319.)

Help families prepare

Advise families whom you refer for evaluation that they are unlikely to have a definitive answer after the first visit. Explain that the evaluation is quite thorough and generally takes several visits. Typically, a child suspected of developmental delay will undergo a comprehensive evaluation, including history and physical exam, blood work (including lead testing and, in some locations, genetic testing), hearing and vision screening, speech and language evaluation, and sensorimotor and cognitive evaluation. Additional information may be requested from daycare providers, preschool teachers, or others who spend significant amounts of time with the child.

Once a diagnosis is made, the team will work with the parents to develop an individualized care plan for the child, which often includes a mix of cognitive, physical, and speech development services in addition to nutrition and support services. The primary care physician, of course, will continue to oversee, monitor, and coordinate care. JFP

Despite a lack of evidence connecting thimerosal to autism, the agent has been removed from most childhood vaccines as a precautionary measure.

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References

1. Developmental Disabilities Monitoring Network Surveillance Year 2010 Principal Investigators; Centers for Disease Control and Prevention (CDC). Prevalence of autism spectrum disorder among children aged 8 years - Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2010. *MMWR*. 2014;63:1-21.
2. American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders*. 5th ed. Arlington, VA: American Psychiatric Publishing: 2013.
3. Council on Children With Disabilities; Section on Developmental Behavioral Pediatrics; Bright Futures Steering Committee; Medical Home Initiatives for Children With Special Needs Project Advisory Committee. Identifying infants and young children with developmental disorders in the medical home: an algorithm for developmental surveillance and screening. *Pediatrics*. 2006;118:405-420.
4. Screening for autism spectrum disorder in young children. US Preventive Services Task Force Web site. Available at: http://www.uspreventiveservicestaskforce.org/uspstf/uspsaut.htm. Accessed November 7, 2013.
5. Johnson CP, Myers SM; Council on Children With Disabilities. Identification and evaluation of children with autism spectrum disorders. *Pediatrics*. 2007;120:1183-1215.
6. Robins DL, Casagrande K, Barton M, et al. Validation of the modified checklist for Autism in toddlers, revised with follow-up (M-CHAT-R/F). *Pediatrics*. 2014;133:37-45.
7. Reichow B, Barton EE, Boyd BA, et al. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD). *Cochrane Database Syst Rev*. 2012;10:CD009260.
8. Rossignol DA, Frye RE. Melatonin in autism spectrum disor-

ders: a systematic review and meta-analysis. *Dev Med Child Neurol*. 2011;53:783-792.

9. Oono IP, Honey EJ, McConachie H. Parent-mediated early intervention for young children with autism spectrum disorders (ASD). *Cochrane Database Syst Rev.* 2013;4: CD009774.
10. Dove D, Warren Z, McPheeters ML, et al. Medications for adolescents and young adults with autism spectrum disorders: a systematic review. *Pediatrics*. 2012;130:717-726.
11. Cheuk DK, Wong V, Chen WX. Acupuncture for autism spectrum disorders (ASD). *Cochrane Database Syst Rev*. 2011;(9):CD007849.
12. Sochocky N, Millin R. Second generation antipsychotics in Asperger's Disorder and high functioning autism: a systematic review of the literature and effectiveness of meta-analysis. *Curr Clin Pharmacol*. 2013;8:370-379.
13. Sinha Y, Silove N, Hayen A, et al. Auditory integration training and other sound therapies for autism spectrum disorders (ASD). *Cochrane Database Syst Rev.* 2011;(12):CD003681.
14. Rossignol DA. Novel and emerging treatments for autism spectrum disorders: a systematic review. *Ann Clin Psychiatry*. 2009;21:213-236.
15. Millward C, Ferriter M, Calver S, et al. Gluten- and casein-free diets for autistic spectrum disorder. *Cochrane Database Syst Rev*. 2008;(2):CD003498.
16. James S, Montgomery P, Williams K. Omega-3 fatty acids supplementation for autism spectrum disorders (ASD). *Cochrane Database Syst Rev*. 2011;(11):CD007992.
17. Williams K, Wray JA, Wheeler DM. Intravenous secretin for autism spectrum disorders (ASD). *Cochrane Database Syst Rev*. 2012;4:CD003495.
18. Green J, Charman T, McConachie H, et al; PACT Consortium. Parent-mediated communication-focused treatment in children with autism (PACT): a randomised controlled trial. *Lancet*. 2010;375:2152-2160.
19. Landa RJ, Holman KC, O'Neill AH, et al. Intervention targeting development of socially synchronous engagement in toddlers with autism spectrum disorder: a randomized controlled trial. *J Child Psychol Psychiatry*. 2011;52:13-21.
20. Kasari C, Gulsrud AC, Wong C, et al. Randomized controlled caregiver mediated joint engagement intervention for toddlers with autism. *J Autism Dev Disord*. 2010;40:1045-1056.
21. Dawson G, Rogers S, Munson J, et al. Randomized, controlled trial of an intervention for toddlers with autism: the Early Start Denver Model. *Pediatrics*. 2010;125:e17-e23.
22. Warren Z, McPheeters ML, Sathe N, et al. A systematic review of early intensive intervention for autism spectrum disorders. *Pediatrics*. 2011;127:e1303-e1311.
23. Anderson KA, Shattuck PT, Cooper BP, et al. Prevalence and correlates of postsecondary residential status among young adults with an autism spectrum disorder *Autism*. 2013 September 9. [Epub ahead of print].
24. Roux AM, Shattuck PT, Cooper BP, et al. Postsecondary employment experiences among young adults with an autism spectrum disorder. *J Am Acad Child Adolesc Psychiatry*. 2013;52:931-939.
25. Orsmond GI, Shattuck PT, Cooper BP, et al. Social participation among young adults with an autism spectrum disorder. *J Autism Dev Disord*. 2013;43:2710-2719.
26. Edelson MG. Are the majority of children with autism mentally retarded? A systematic evaluation of the data. *Focus Autism Other Dev Disabl*. 2006;21:66-83.
27. Wakefield AJ, Murch SH, Anthony A, et al. Ileal-lymphoid-nodular hyperplasia, non-specific colitis, and pervasive developmental disorder in children. *Lancet*. 1998;351:637-641.
28. Uhlmann V, Martin CM, Sheils O, et al. Potential viral pathogenic mechanism for new variant inflammatory bowel disease. *Mol Pathol*. 2002;55:84-90.
29. Centers for Disease Control and Prevention: Immunization Safety and Autism. Centers for Disease Control and Prevention Web site. Available at: http://www.cdc.gov/vaccinesafety/Concerns/Autism/Index.html. Accessed May 20, 2014.
30. Centers for Disease Control and Prevention (CDC). Thimerosal in vaccines: a joint statement of the American Academy of Pediatrics and the Public Health Service. *MMWR Morb Moral Wkly Rep*. 1999;48:563-565.
31. IDEA. Autism Community Web site. Available at: http://www.autism-community.com/education/idea/. Accessed May 20, 2014.