Autism Spectrum Disorder

Health Watch Table

The most recent report from the Centers for Disease Control (2023) estimates the prevalence rate of autism spectrum disorder in children aged 8 years is 27.6 per 1000 children (1 in 36). ASD is 3.8 times as prevalent among boys (4.3%) as among girls (1.1%). Autism spectrum disorder is a neurodevelopmental condition characterized by impairments in social interactions, inflexible repetitive behaviors, and difficulties in communication. In 2013, the fifth edition of the Diagnostic and Statistical Manual (DSM-V) released a revised criteria for the diagnosis of autism. Firstly, pervasive developmental delay, autism and Aspergers syndrome were combined into a single diagnosis of autism spectrum disorder. To meet the diagnostic criteria, according to the recently revised DSM V (DSM-5 TR), a person must have persistent deficits in each of *all* the domains of the social communication and interaction criteria. Plus at least two of four types restricted repetitive behaviors must be present (DSM-5-TR). Severity is based on social communication impairments and restricted, repetitive patterns of behavior. For either criterion, severity is described in three levels: Level 3 – requires very substantial support, Level 2 – Requires substantial support, and Level 1 – requires support.

1. Head, eyes, ears, nose, throat

Considerations	Recommendations
▸ *Children*: Hearing: Recurrent otitis media is common ▸ Nasal: Nasal allergies are common ▸ Both of these conditions may be undertreated due to communication difficulties that interfere with the child expressing pain or discomfort. ▸ *Children and Adults*: Greater risk of significant hearing loss ▸ Hyperacusis is common ▸ Vision: Sensitivity to light is common ▸ Strabismus and refractive errors may be more prevalent ▸ Hearing deficits can be a factor in speech delay.	▸ Visualize tympanic membranes at each visit. ▸ Consider referral to otolaryngologist if otitis media persists. ▸ Screen hearing and vision regularly ▸ Screen for nasal allergies ▸ Review hearing and vision and assess as required when changes in behavior are noted.

2. Dental

Considerations	Recommendations
▸ *Children and Adults*: Dental caries are common. Individuals with sensory sensitivities may not be thorough in toothbrushing, and restricted diets may predispose some to dental caries. ▸ Bruxism may lead to excessive tooth surface wear/ damage and predispose to decay.	▸ Refer to a dentist for semi-annual exams, or more frequently if indicated. ▸ Consider treatment for bruxism, if present

3. Sleep

Considerations	Recommendations
▸ *Children and Adults*: Difficulty initiating or maintaining sleep is common (50%-80%). ▸ Research shows that sleep problems in ASD exacerbate core ASD symptoms, such as presence of repetitive behaviors, poor social interactions, and communication difficulties	▸ Ascertain a sleep history, including whether habits are in place to promote sleep (e.g., adequate physical exercise , minimizing caffeine and, in the case of adults, alcohol, and limiting use of electronic devices close to bedtime). ▸ Evaluate for causes of night wakings, including obstructive sleep apnea, restless legs syndrome/ periodic leg movements of sleep (which may be more common in this population due to low iron from restricted diets), nocturnal seizures, and parasomnias (sleepwalking, sleep terrors, confusional arousals). ▸ Implement simple behavioral strategies to improve sleep habits. Refer to a sleep specialist and/or for a sleep study as appropriate. ▸ Single-ingredient melatonin is safe and often effective for children and adults with ASD and sleep difficulties. ▸ Video: Should I give melatonin to my child with autism?

4. Gastrointestinal

Considerations	Recommendations
▸ *Children and Adults*: Constipation, diarrhea, gastroesophageal reflux disease (GERD), and food adversions/preferences are common. ▸ Some individuals may be on specialized diets, e.g., gluten-free, casein-free diet. ▸ Food allergies are also common. ▸ Under-nutrition due to strict food preferences or oral hypersensitivity, and nutritional difficulties are also common, especially among individuals on chronic anti-seizure medications.	▸ Refer to a gastroenterologist, nutritionist, or dietician, as appropriate. Depending on the nature and severity of the gastrointestinal problems, treatments can include dietary interventions, behavioral interventions focused on feeding and diet, nutritional supplements, and medications that address gastrointestinal disorders. ▸ Ascertain whether the individual is on a specialized diet and if so, whether nutritional needs are being met since these individuals may be at risk for nutritional deficiencies. ▸ Screen for pica and obtain serum lead levels when pica exists. ▸ Monitor for suboptimal growth and nutritional deficiencies if food selectivity exists.

5. Sexual Function

Considerations	Recommendations
▸ *Adults*: Males and females are fertile.	▸ Consider discussion of recurrence risk and reproductive options, with possible referral to gynecologist. ▸ Consider birth control when girls begin menstruation to avoid unwanted pregnancy. ▸ Consider evaluation by geneticist if patient and/or family is interested in determining whether a genetic etiology can be identified.

6. Musculoskeletal (MSK)

Considerations	Recommendations
▸ *Children*: Hypotonia is common (~ 50%) ▸ Hypotonia gradually improves over time.	▸ Consider evaluation by neurologist. ▸ Physical therapy can improve gross motor control and overall body strength. Occupational and speech-language therapy can help with fine motor control, speech, and feeding difficulties.

7. Neurology

Considerations	Recommendations
▸ *Children and Adults*: Seizures are relatively common (6%-30%). ▸ Some individuals may experience onset of seizures during puberty. These seizures may be subtle and not readily observable. ▸ Motor dysfunction is common (gross and fine motor delays, apraxia, and difficulty with walking and coordination). ▸ Motor apraxia improves over time. ▸ Tic disorders are more common (Tourette syndrome or chronic motor tic). ▸ A small proportion of youth and young adults develop catatonia-like behavior. Etiology remains unclear but may be related to stress.	▸ Ascertain a history of staring spells, loss of consciousness or awareness, and convulsive activity. Refer to a neurologist and/or for an EEG as appropriate. ▸ Consider evaluation with neurologist if adolescent begins to exhibit significant behavior problems, e.g., aggression or self-injury, or if academic progress is affected and/or if regression in acquired language occurs. ▸ Ascertain a history of motor difficulties. Refer to a physical therapist or an occupational therapist as needed for evaluation and/or treatment. ▸ Multidisciplinary approach is crucial for assessment of catatonia-like behavior and treatment.

8. Behavioral/mental health

Considerations	Recommendations
▸ *Children and Adults*: Individuals may have impaired social relationships. Some may not show an interest in social interactions while others seek interaction but are not skilled in how to proceed. ▸ Individuals often have restricted patterns of interests or repetitive behaviors. Young children may rock, stare, or twirl strings. ▸ Elopement/wandering is common, particularly in children. ▸ Individuals of all ages may express a need for sameness in daily routines. ▸ Meltdowns self-injurious or aggressive behaviors are common. ▸ Co-morbid psychiatric problems are common. Individuals may have more than one condition, with a high prevalence of psychotropic medication treatment in this population. Conditions include depression, anxiety, obsessive-compulsive disorder, and attention deficit hyperactivity disorder.	▸ Regular surveillance for behavioral issues or mental health conditions is important. Refer for behavioral therapy and psychiatric intervention as appropriate.

9. Infectious disease/Immune Deficiency

Considerations	Recommendations
▸ *Children and Adults*: ~ 25% have immune deficiency and dysfunction. This may manifest as frequent infections (e.g., ear, sinus, upper respiratory).	▸ Consider referral to infectious disease specialist if infections occur frequently

10. Etiology

Considerations	Recommendations
▸ Autism spectrum disorder is a behaviorally defined entity. While most individuals with ASD have a "multifactorial etiology," some have identifiable etiologies, such as Fragile X, Smith-Lemli-Optiz syndrome, 22q duplication syndrome or tuberous sclerosis, which may help guide treatment. ▸ An identified genetic etiology may be made for as many as 30% to 40% of ASD cases.	▸ Consider evaluation by geneticist especially for those with severe developmental delays, dysmorphic features, congenital anomalies, and family history of ASD. ▸ Consider evaluation even for individuals who have undergone a genetic appraisal in childhood with negative results.

11. Language and Communication

Considerations	Recommendations
▸ Up to 25% of children and adults do not develop functional spoken language and communicate through behavior, facial expressions, and body language ▸ Early intervention can improve communication skills ▸ Difficulties may include receptive and/or expressive language, poor motor control and social aspects of language ▸ Loss of language skills in children– key regression sign for clinicians to undertake autism screening ▸ Language skills will continue to develop into adulthood	▸ Early enrollment in speech and language program and early intervention services ▸ Evaluation by speech-language pathologist and possible use of augmentative and alternative communication systems, such as the Picture Exchange Communication System or devices or other r tools/ strategies such as visual aids like video modeling, Books Beyond Words, Social Stories

12. Sensory

Considerations	Recommendations
Children & Adults: ▸ ~ 90% may have unusual hyper- and/or hypo-sensory sensitivities or responses in sensory domains including hearing, vision, tactile, olfactory, taste, proprioceptive, and vestibular These can give rise to substantial problems in their daily lives and may not always be apparent (e.g., some report sensitivities to barometric pressure) ▸ Certain unusual behaviors can indicate sensory hypersensitivities, e.g., fingers in ears in response to sounds, squinting, hands over eyes with flickering and buzzing fluorescent lighting; squirming to touch may indicate tactile defensiveness. ▸ Overstimulation, related to difficulties processing sensory input, especially verbal, but also other information, can give rise to sensory overload and present as "meltdowns"	▸ Refer to occupational therapist for assessment of the individual's unique profiles of hyper- and hypo-sensory sensitivities and responses. Support implementation of a sensory diet as required ▸ For many individuals, the right balance of sensory stimuli is important and may be calming (e.g., deep pressure is calming, while light touch may be distressing). ▸ Strategies are also available to manage sensory stimuli that are overwhelming, e.g., wearing noise-muting headphones, fidget toys or objects and bouncing on a ball (proprioceptive and vestibular).

12. Sensory (continued)

Considerations	Recommendations
▸ Engaging in repetitive behaviors (e.g., pacing) and "self-stimming" behaviors (e.g., rocking) may be a way to self-calm and avoid going into an autonomic nervous system hyper-arousal state. Hypo-sensitivities may manifest in antisocial behaviors, (e.g., pressure-seeking behaviors by squeezing self or others). Unusual gait, such as toe walking, kicking at surfaces and hyperactivity, may indicate proprioceptive and vestibular difficulties or distortions.	

13. Other

Considerations	Recommendations
▸ Up to 40% of individuals with ASD may have an intellectual disability. ▸ There is no evidence that people with ASD suffer any less from a painful/noxious experience. ▸ Pain may present as distressing behavior, such as aggression or self-injury or as agitation. ▸ Pain may present as changes in food and fluid consumption.	▸ It is important to have an accurate measure of underlying cognitive potential determined by a psychologist or other qualified examiner, including nonverbal measures. Such psychological assessments may need to be repeated periodically through childhood. ▸ Music, movement, and deep pressure may help ease pain for some patients. ▸ Consider symptomatic treatment for perceived pain with analgesics. ▸ Monitor for resolution of pain or target behaviors associated with pain.

Originally published as Autism Health Watch Table. Malow, B.A., Shouse, J. Vanderbilt Kennedy Center, Nashville, TN, updated 2023.

This tool was reviewed by physicians on the Toolkit's Advisory Committee; for list, view here.

Four published autism spectrum disorder health care guidelines were reviewed and compared.

- Anagnostou E, Zwaigenbaum L, Szatmari P, Fombonne E, Fernandez BA, Woodbury-Smith M, Brian J, Bryson S, Smith IM, Drmic I, Buchanan JA, Roberts W, Scherer SW, Autism spectrum disorder: advances in evidence-based practice. *CMAJ* 2014 doi:10.1503/cmaj.121756. Epub 2014 Jan 13, www.cmaj.ca/content/early/2014/01/13/cmaj.121756. Accessed July 2021.
- Coury, DL, Medical Treatment of Autism Spectrum Disorders. *Current Opinion in Neurology* 2010 Apr; 23 (2) 131-136. doi: 10.1097/WCO.0b013e32833722fa. journals.lww.com/co-neurology/Abstract/2010/04000/Medical_treatment_of_autism_spectrum_disorders.8.aspx. Accessed July 2021.
- Maski KP, Jeste S; Spence SJ, Common neurological co-morbidities in autism spectrum disorders. *Current Opinion in Pediatrics* 2011 Dec; 23 (6) 609-615. doi: 10.1097/MOP.0b013e32834c9282. journals.lww.com/co-pediatrics/Abstract/2011/12000/Common_neurological_co_morbidities_in_autism.8.aspx. Accessed July 2021.
- Malow BA, Byars K, Johnson K, Weiss S, Bernal P, Goldman SE, Panzer R, Coury DL,Glaze DG, A Practice Pathway for the Identification, Evaluation, and Management of Insomnia in Children and Adolescents With Autism Spectrum Disorders. *Pediatrics* 2012; 130:S106-S124. http://pediatrics.aappublications.org/content/130/Supplement_2/S106.full. Accessed July 2021.

References:

Data & Statistics on Autism Spectrum Disorder from the Centers for Disease Control and Prevention, and then list the website: https://www.cdc.gov/ncbddd/autism/data.html

Veatch OJ, Sutcliffe JS, Warren ZE, Keenan BT, Potter MH, Malow BA. Shorter sleep duration is associated with social impairment and comorbidities in ASD. Autism research: official journal of the International Society for Autism Research. 2017;10(7):1221-1238.

Ashwood P, Krakowiak P, Hertz-Picciotto I, Hansen R, Pessah I, Van de Water J, **Elevated plasma cytokines in autism spectrum disorders provide evidence of immune dysfunction and are associated with impaired behavioral outcome.** *Brain Behav Immun.* 2011 Jan; 25(1):40-5. doi: 10.1016/j.bbi.2010.08.003. Epub 2010 Aug 10. www.ncbi.nlm.nih.gov/pubmed/20705131. Accessed July 2021.

Rosenhall U, Nordin V, Sandstrom M, Ahlsen G, Gillberg C., Autism and Hearing Loss*. Journal of Autism and Developmental Disorders,* 1999; 29(5). link.springer.com/article/10.1023%2FA%3A1023022709710#page-1. Accessed July 2021.

Kern JK, Trivedi MH, Garver CR, Grannemann BD, Andrews AA, Savla JS, Johnson DG, Mehta JA, Schroeder JL, **The pattern of sensory processing abnormalities in autism.** *Autism.* 2006 Sep;10(5):480-94. www.ncbi.nlm.nih.gov/pubmed/16940314. Accessed July 2021.

Ming X, Brimacombe M, Wagner GC, **Prevalence of motor impairment in autism spectrum disorders.** *Brain Dev.* 2007 Oct; 29(9):565-70. Epub 2007 Apr 30. www.ncbi.nlm.nih.gov/pubmed/17467940. Accessed July 2021.

Canitano R, Vivanti G, Tics and Tourette syndrome in autism spectrum disorders. *Autism,* 2007 Jan; 11(1) 19-28. doi: 10.1177/1362361307070992. aut.sagepub.com/content/11/1/19.short. Accessed July 2021.

Simmons DR, Robertson AE, McKay LS, Toal E, McAleer P, Pollick FE. **Vision in autism spectrum disorders.** *Vision Res.* 2009 Nov;49(22):2705-39. doi: 10.1016/j.visres.2009.08.005. Epub 2009 Aug 12. www.ncbi.nlm.nih.gov/pubmed/19682485. Accessed July 2021.

Lane AE, Young RL, Baker AEZ, Angley MT, **Sensory Processing Subtypes in Autism: Association with Adaptive Behavior.** *Journal of Autism and Developmental Disorders*, 2010 Jan; 40 (1) 112-122. link.springer.com/article/10.1007%2Fs10803-009-0840-2. Accessed July 2021.

Buie T, Campbell DB, Fuchs GJ 3rd, Furuta GT, Levy J, Vandewater J, Whitaker AH, Atkins D, Bauman ML, Beaudet AL, Carr EG, Gershon MD, Hyman SL, Jirapinyo P, Jyonouchi H, Kooros K, Kushak R, Levitt P, Levy SE, Lewis JD, Murray KF, Natowicz MR, Sabra A, Wershil BK, Weston SC, Zeltzer L, Winter H. Evaluation, diagnosis, and treatment of gastrointestinal disorders in individuals with ASDs: a consensus report. Pediatrics. 2010 Jan;125 Suppl 1:S1-18. doi: 10.1542/peds.2009-1878C. PMID: 20048083.

Mazzone L, Postorino V, Valeri G, Vicari S. Catatonia in patients with autism: prevalence and management. CNS Drugs. 2014 Mar;28(3):205-15. doi: 10.1007/s40263-014-0143-9. PMID: 24504828.

Schaefer GB, Mendelsohn NJ; Professional Practice and Guidelines Committee. Clinical genetics evaluation in identifying the etiology of autism spectrum disorders: 2013 guideline revisions. Genet Med. 2013 May;15(5):399-407. doi: 10.1038/gim.2013.32. Epub 2013 Mar 21. Erratum in: Genet Med. 2013 Aug;15(8):669. PMID: 23519317.

Allely CS. Pain sensitivity and observer perception of pain in individuals with autistic spectrum disorder. ScientificWorldJournal. 2013 Jun 13;2013:916178.

American Psychiatric Association. (2022). *Diagnostic and statistical manual of mental disorders*(5th ed., text rev.). American Psychiatric Publishing.

Leekam SR, Nieto C, Libby SJ, Wing L, Gould J. Describing the sensory abnormalities of children and adults with autism. J Autism Dev Disord. 2007 May;37(5):894-910

Bogdashina O. Sensory perceptual issues in autism and Asperger syndrome: different sensory experiences – different perceptual worlds. London: Jessica Kingsley; 2003.

Caminha RC, Lampreia C. Findings on sensory deficits in autism: Implications for understanding the disorder. Psychol Neurosci. 2012;5(2):231-7.