

Speaker Disclosure We have no disclosures.

## Learning Objectives

- · Identify cultural and linguistic variables critical to autism spectrum disorder (ASD) assessment for children from diverse backgrounds.
- State the different components of the ECLECTIC framework.
- Demonstrate clinical application of the ECLECTIC framework.
- Discuss best practice recommendations for providing culturally-informed ASD evaluations.

## **Autism Spectrum Disorders**

- Collection of neurodevelopmental disorders that are characterized by impairments in social interaction and communication, as well as the presence of restricted and repetitive behaviors and interests.
- Affect approximately 1 in 36 children in the US (CDC, 3/2023; Maenner MJ, Warren Z, Williams AR, et al. 2023)
   This is over 1.5 million children
- Global estimate 1 in 160 children • Increased male to female ratio (~4.2:1)
- 35.2% had an IQ ≤70
- We do not have a specific cause
- Seen across all races, ethnic groups, socioeconomic strata, but...

2

## Cultural Differences - Longstanding Research

- Hispanic/Latinx children are often

  - misdiagnosed with ASD and are
     diagnosed 2 ½ years later than their White peers
- Those with 2 US-born parents > 2 foreign-born parents
- Black youth are more likely to be
  - misdiagnosed with conduct disorder and adjustment disorder instead of ASD



## Longstanding Research cont.

- Black, Hispanic/Latinx, and other racial/ethnic and linguistically-diverse minority youth are
   less likely to have documentation of ASD in their school and health records
- Children from a Hispanic/Latinx or Asian culture with an IQ in the intellectual disability range are
  - less likely to be diagnosed with ASD, while for Black children the disparity persists

6

## Cultural Differences- ADDM report 2022

- 2018 data
- Overall similar prevalence by race and ethnicity at age 8, but
  - American Indian/Alaska Native > White children
- Variability across sites demonstrated:
  - Hispanic/Latinx children < Black or White children for dx
  - Black children (49.8%) > White (29.7%) and Hispanic/Latinx (33.1%) to be diagnosed with intellectual disability



## ADDM report 2022 cont.

- · Variability across sites with respect to median household income:
  - 5 of 11 sites demonstrated lower prevalence with higher
  - 1 of 11 demonstrated higher prevalence with higher MHI
  - The other 5 did not demonstrate association with MHI

## Cultural Differences- ADDM report 2023

- 2020 data
- Increased ASD prevalence by race and ethnicity at age 8, compared to 2018
  - American Indian/Alaska Native (26.5) > White children (24.3) no
  - Black (29.3), Hispanic/Latinx (31.6) and Asian/Pacific Islander (33.4) > White children and those from 2 or more races (22.9) - **NEW**
  - 30% increase for Asian, Black, and Hispanic/Latinx children
  - Similar trend for children age 4 in 2018



ADDM report 2023 cont.

- Intellectual Disability
   Remained similar for Black children (50.8%) > Asian/Pacific Islander (41.5%), Hispanic/Latinx (34.9%), and White (31.8%) children
   Slightly higher percentages compared to 2018 for all
- Variability across sites with respect to median household income:
   Lower prevalence with higher household income at 3 sites
   No association at other 8 sites

10

#### Other Cultural Differences

- Girls from cultural/ethnic minority groups
  - Gender-specific roles/expectations
  - · Play and social interactions
- · Gender diverse youth
  - · Report more autistic traits than cisgender youth
- · Intersectionality is key!



So why the difference?

•Healthcare Access? Distrust?

•Healthcare Literacy and Awareness of ASD?

•Literacy or Acculturation?

•Clinician bias?

·Misdiagnosis?

•Cultural Stigma?

## Diagnostic Criteria according DSM-5-TR

- Persistent deficits in social communication and social interaction across multiple contexts, as manifested by all of the following, currently or by history:
   Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
  - 2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and onverbal communication.
  - 3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.



#### And....

- 2. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history:
  - 1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).

    2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of
  - verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same
  - 3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests)
  - 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights

14

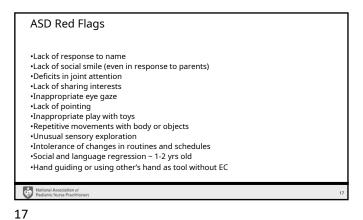
13

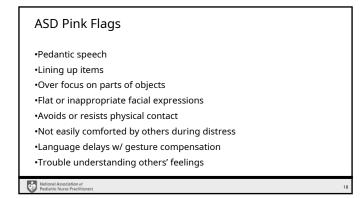
- Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life)
- Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.
- These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

**Red flags:** clearly diagnostic, classic symptoms

Pink flags: subtle associated features, less definitive symptoms- investigate and explore



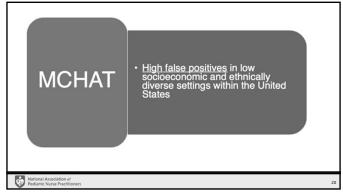


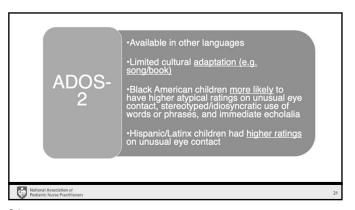


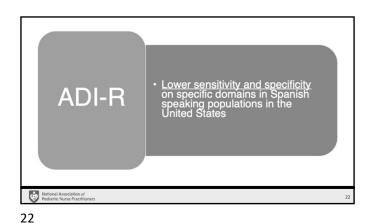
Screening & Diagnostic Tools

M-CHAT-R<sup>IM</sup>

Please answer their questions about your child. Keep in mind how your child goally behaves. If you have seen your child do the behavior as fermious, but for or their outsulpy die. It have please answer rea. Please circle year (and life of the behavior) are fermious, but for or their outsulpy die. Their please areaser rea. Please circle year (and life of the child live) at 12 if the please areaser rea. Please circle year (and life of the l







#### Who evaluates for ASD?

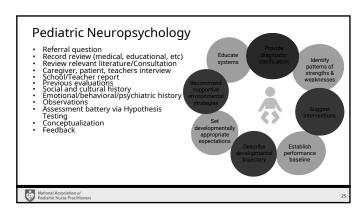
- · Varies by state, insurance requirements, scope of training
  - · Developmental behavioral pediatricians, advanced practice providers, general pediatricians
  - Educational diagnosticians
  - Psychologists and neuropsychologistsSpeech/language pathologists

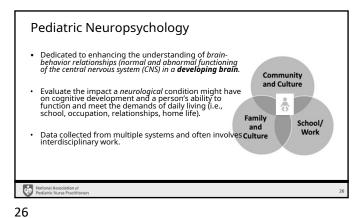
  - Neurologists
  - Psychiatrists

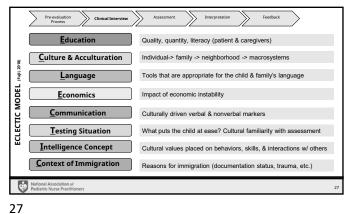


## When is pediatric neuropsychology recommended?

- 1) To obtain information about developmental trajectories of learning, attention, adaptive skills, or behavior issues in the context of:
- Brain based disorders or suspected brain insult
- Genetic syndromes
- Complex medical history
- In utero exposures
- Challenging diagnostic presentation
- 2) Gradual or sudden unexplained change in the child's usual functioning.









#### Case One

- · Developmental Behavioral Pediatrics Clinic
- · Culturally informed evaluation: bilingual, bicultural boardcertified pediatric neuropsychologist with expertise in neurodevelopmental disorders and medical complexity.
- · Assessed over the course of a single day.



29

Case One

A 3-year old girl of Latin American background referred by her developmental behavioral pediatrician for diagnostic clarification.

Background:

- PMH: prematurity (34 weeks), microcephaly, severe hypoxic ischemic encephalopathy in NICU course 2/2 seizures, and bilateral sensor ineural hearing loss (received cochlear implants at 18
- months.)
  Bilingual household (Spanish/English): her dominant language is Spanish.

Parents' Chief Complaint:
Concern for developmental delays, attention/regulation, and sensory issues (biting self).

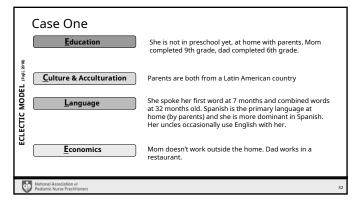
30

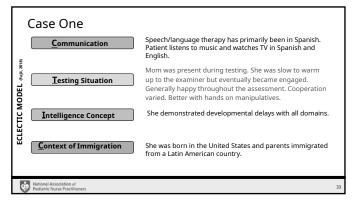
Case One

**Testing Observations** 

- Patient demonstrated social referencing, eye contact when requesting, pointing with whole hand, directed smiling.
  Limited speech, was able to vocalize few consonant-vowel combinations (ie. "Ma" "ta")
  Did not engage in relational play, engaged in pretend play by herself (drank from an empty cup, combed her hair)
  Able to complete puzzle pieces in a board, pegs in pegboard.
  Frequent fisting of hands, forceful motions when working with manipulatives
- manipulatives No repetitive behaviors, no stereotypies other than one possible instance of flapping with brief excitement Unable to stand on her own or take steps without support







# Case One

34

Testing performed: Bayley-4, ASRS, Vineland-3

Diagnostic impressions:

- Global Developmental Delay secondary to severe hearing loss and severe HIE
  - Overall developmental abilities ~15 months
    Language ~ 11 to 13 months
    Motor ~13 to 17 months
    Adaptive abilities/personal care ~18 months

  - Social skills~ 14 to 16 months
- Recommended re-evaluation in 1 year, post speech/language
- consider ASD at that time

33

## Case Two

- Multidisciplinary Clinic
  - Speech pathologist, occupational therapies, trainees, developmental behavioral pediatrician/psychiatrist, and psychologist
- · Assessed over the course of three appointments
- Access to language services and interpreters
- · Culturally informed evaluation

Case Two

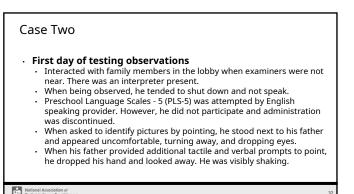
A 6-year-old boy of Mexican background referred by PCP

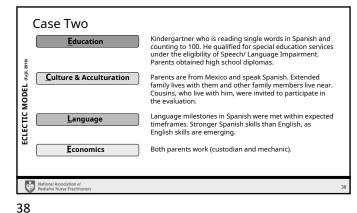
Background:

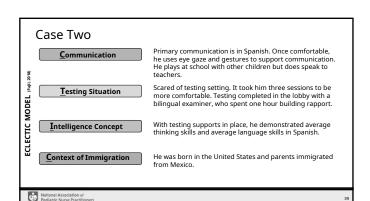
- General good health and no prescribed medications.
- History of stuttering and language delays.
- Academic diagnosis of speech/language impairment and autism per IEP and speech and language therapy at school and community. Stronger understanding and expression in Spanish in comparison to

Parents' chief complaint:
Concerns related to emotional regulation, communication, and social interactions at school.

36







Case Two

Testing performed: DAS-II, Sensory Profile 2, CARS-2, BASC-3, Vineland-3
Diagnostic impressions:

• Selective Mutism
• Social Anxiety Disorder

Results:

• Average intellectual functioning
• Average verbal abilities in Spanish
• Age appropriate social overtures, nonverbal communication, and play with same age peers
• No reported restricted and repetitive behaviors
• Symptoms endorsed regarding anxiety around new social situations and not speaking (selective mutism) to teachers at school and new adults

Recommendations:
• Speech and language therapy, school services, and psychotherapy

#### Take-aways from the ECLECTIC Framework

- ADOS-2 can still be valid and impactful BUT emphasis on scores without a cultural lens is problematic.
- Pre-think and preparing about how you ask questions.
  - Create a cultural interview and practice it!
  - · Start slow and add as you grow in comfort
  - Be prepared to create space and spend time
- Think about symptoms within the cultural concept for that child, from that particular culture, living with that particular family.



41

#### **Special Considerations**

- *Ethics:* Barriers to communication merit <u>targeted efforts</u> on the part of the clinician to disentangle cultural differences from developmental ones.
- Cultural differences in the use of eye contact, gestures, perceptions of social norms and behaviors, as well as varying educational experiences and comfort levels with clinicians represent some of the critical barriers to assessment and diagnosis of ASD.

National Association of Pediatric Nurse Practitioners

42

## **Special Considerations**

- Advocacy: The ECLECTIC model provides a valuable framework for comprehensive assessment of children from various racial, linguistic, and ethnic groups.
- It can also serve as a <u>reference point</u> for entry into dialogue with patients and families when there are atypical social skills or behaviors and interests that may be indicative of ASD.SD.

National Association of Pediatric Nurse Practitioners

## **Special Considerations**

• Interprofessional practice: encourage collaboration and interprofessional practice with a range of disciplines to clarify strengths and challenges (with goal of tailoring interventions accordingly).

National Association of Pediatric Nurse Practitioner

#### **Practice Recommendations**

- Determine the child's dominant language and language proficiency prior to the evaluation.
- Late diagnosis may require more intensive intervention to compensate for previous inappropriate or insufficient services or learning environments.
- Consider that traumatic experiences may be associated with atypical behaviors and social interactions that need to be distinguished from symptoms of autism.



#### **Practice Recommendations**

- Immigration status in the U.S. may impact parents' desire to seek evaluation for their child secondary to access to services as well as fears of how results can impact citizenship decisions.
- Document the educational level attained of the child and parent in reports, as well as how this could influence testing.
- Attempts should be made to understand a family's cultural perception of behavioral and social norms that affect educational expectations.
  - Identify family's knowledge, attitudes, and values re: child's development and behaviors.

45

46

#### References

American Education Research Association, American Psychological Association, & the National Council on Measurement in Education. (2014). Standards for educational and psychological testing (2nd ed.), American Education Research Association.

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.).

American Psychological Association. (2017). Multicultural guidelines: An ecological approach to context, identity, and intersectionality. http://www.aps.org/about/policy/milcultural-guidelines: An ecological approach to context, identity, and intersectionality. http://www.aps.org/about/policy/milcultural-guidelines: An ecological approach to context, identity, and intersectionality. http://www.aps.org/about/policy/milcultural-guidelines: An ecological approach to context, identity, and intersectionality.

Attwood, T. (2006). Asperger syndrome and girls: The pattern of abilities and development of girls with Asperger's syndrome. Future Horizons.

Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: Autism. Child and Adolescent Psychiatric Clinics of North America, 19, 855–867. https://doi.org/10.1016/j.chc.2010.07.005 Bernier, R., Mao, A., & Yen, J. (2010). Psychopathology, families, and culture: autism. Child Adolesc Psychiatr Clin N Am, 19(4), 855–867. https://doi.org/10.1016/j.chc.2010.07.005

https://doi.org/10.1016/j.ch.2010J/J.005
Blanche, E. I., Dilzu J., Earetto, T. A. Cermak, S. A. (2015). Caregiver experiences of Latino families with autism spectrum disorder. American Journal of Occupational Therapy, 68(6), 6905165016j. <a href="https://doi.org/10.2013/10/2642-015.0072888">https://doi.org/10.2013/10/26488</a>
Bordes Edgar, V., Meneses, V., Shaw, D., Romere, R. A., Salinas, C. M. & Kissel, A. (2022). Clinical utility of the ECLECTIC framework in providing culturally-informed autism spectrum disorder evaluations: A pediatric case-based approach. The Clinical neuropsychologist, 36(5), 1148-1171. https://doi.org/10.1080/18554046.2201.1396187

Burkett, K., Morris, E., Manning-Courtney, P., Anthony, J., 8 Shambley-Ebron, D. (2015), African American families on autism diagnosis and treatment. The influence of culture. Journal of Autism and Developmental Disorders, 45, 3244–3254. https://doi.org/10.1007/s10803-015-2482-x



#### References

Canas, A., Bordes Edgar, V., & Neumann, J. (2020). Practical considerations in the Neuropsychological Assessment of Bilingual (Spanish-English) Children in the United States: Literature review and case series. Developmental Neuropsychology, 45(4), 211–231. https://doi.org/10.1080/

Imms/1000ft/j IU. reviews 3000 in Journ 1 Journ 1 Journ 2 Jour

Constantino, et al. (2020). Timing of the diagnosis of autism in African American children. Pediatrics, 146(3), e20193629. https://doi.org/10.1542/peds.2019-3629

Cormier, D., Davidson, E., Young, A., & Augustyn, M. (2018). A young man with Trisomy 21 and sudden behavioral changes. Journal of Developmental and Behavioral Pediatrics, 39, 1–3.

Cory, J. M. (2021). White privilege in neuropsychology: An 'invisible knapsack' in need of unpacking? The Clinical Neuropsychologist, 35(2), 206–213. https://doi.org/10.1080/13854046.2020.1801845

Daugherty, J. C., Puenta, A. E., Falsous, A. F., Hiddiga-Ruzante, N., & Perez-Garcia, M. (2017). Diagnostic mistakes of culturally diversindividuals when using North American neuropsychological tests. Applied Neuropsychology Adult, 24, 16–22. https://doi.org/10.1080/23276905.2015.108892

Dean, M., Harwood, R., & Kasari, C. (2017). The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder. Autism, 21(6), 678–689.https://doi.org/10.1177/1362361316671845

48

#### References

Dean, M., Kasari, C., Shih, W., Frankel, F., Whitney, R., Landa, R., Lord, C., Orlich, F., King, B., & Harwood, R. (2014). The peer relationships of girls with ASD at school: comparison to boys and girls with and without ASD. Journal of Child Psychology and Psychiatry, 55(11), 1218– 1225. https://doi.org/10.1111/jop.12242

Denmark, T., Atkinson, J., Campbell, R., & Swettenham, J. (2019). Signing with the face: Emotional expression in narrative production in deaf children with autism spectrum disorder. Journal of Autism and Developmental Disorders, 49, 294–306. https://doi.org/10.1007/s10803-

Durkin, M. S., Maenner, M. J., Baio, J., Christensnen, D., Daniels, J., Fitzgerald, R., Imm, P., Lee, L., Schieve, L. A., Braun, K. V. N., Wingate, M. S., & Yeargin-Allsopp, M. (2017, November). Autism spectrum disorder among US children (2002–2010): Socioeconom racial, and ethnic disparities. American Journal of Public Health. 10/11. 1818–1826. https://doi.org/10.2105/JA/PH.2017.340432

Dyches, T. T. (2011). Assessing diverse students with autism and the role of SLPs: ASHA documents offer guidance. Leader, 16, 11–15. www.asha.org/leader.aspx.

El-Ghoroury, N. H., & Krackow, E. (2012). Enhancing the identification of autism spectrum disorders via a model of culturally sensitive childhood assessment. Professional Psychology: Research and Practice, 43(3), 249–255. https://doi.org/10.1037/a0027354 Elsabbagh, M., Divan, G., Koh, Y., Kim, Y. S., Kauchali, S., Marcin, C., Monfel-Nava, C., Patel, V., Paula, C. S., Wang, C., Yasamy, M. T., & Fomborne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. Autism Research, 5, 160–179. https://doi.org/10.1002/amiz/28

Farver, J. M., Kim, Y. K., & Lee, Y. (1995), Cultural differences in Korean- and Anglo-American preschoolers' social interaction and play behaviors. Child Development, 66, 1088–1099. https://doi.org/10.2307/1131800



#### References

Fujli, D. E. M. (2018). Developing a cultural context for conducting a neuropsychological evaluation within a culturally diverse client: the ECLECTIC framework. The Clinical Neuropsychologist, 32(8), 1356–1392. https://doi.org/10.1080/1385446.2018.143592.

intigs: //LOUNGY 16.1000/153090402-016.14350626
Moerner, M. J., Wang, T., Williams, A., A-mostohene, E., Bakian, A. V., Bilder, D. A., Durkin, M. S., Fitzgerald, R. T., Furnier, S. M., Hughes, M. M., Ladd-Acosta, C. M., McArbur, D., Pate, E. T., Salinss, A., Vehon, A., Williams, S., Esler, A., Gorybowski, A., Hall-Lande, J., Njoyen, R. H. N., ... Shaw, K. A. (2023). Prevalence and Challenderiselised of Aulism Spectrum Disorder Auron, Disburdering Network (Incomposited Desiblishing Monoting Network). But United States, 2020. Mchicility and mortality weekly report. Surveillance summaries (Washington, D. C.: 2003), 72(p), 1–14. https://doi.org/10.15585/mmer.ss720261

S. N., & Rice, C. (2012). Association between parental nativity and autism spectrum disorder among US-born non-Hispanic white and Hispanic children, 2007 National Survey of Children's Health. Disability Health Journal, 5 (1), 18–25, <a href="https://doi.org/10.1018/j.iplp.2011.09.01">https://doi.org/10.1018/j.iplp.2011.09.01</a>

Shorey, S., Ng, E. D., Haugan, G., & Law, E. (2020). The parenting experiences and needs of Asian primary caregivers of children with autism: A meta-analysis. Autism; 24(3), 591–604. https://doi.org/10.1177/1362361319886513

Stein, D., Munir, K., Karweck, A., Davidson, E., & Stein, M. (2013). Developmental regression, depression, and psychosocial stress in an adolescent with DS. Journal of Developmental & Behavioral Pediatrics, 34(3), 216–218. https://doi.org/10.1097/DBP.0b013e31828b2b42

Stotl, C., Pallus-Germain, R., Caldara, R., Lao, J., Dys. M. W., Aptel, F., & Psacalis, O. (2016), January). Face recognition is shaped by the use of sign language. The Journal of Deaf Studies and Deaf Education, 23(1), 62–70. https://doi.org/10.1093/deafed/en/034.

Sweet, J. J., Klofel, K. K., Nelson, N. W., & Moberg, P. J. (2021). Professional practices, beliefs, and incomes of U.S. neuropsychologists: The AACN, NAN, SCN 2020 practice and salary survey. The Clinical Heuropsychologist, 35(1), 7–80. https://doi.org/10.1080/13854046.2020.1849803

Szarkowski, A., Mood, D., Shield, A., Wiley, S., & Yoshinaga-Itano, C. (2014). A summary of current understanding regarding children with autism spectrum disorder who are deaf or hard of hearing. Seminars in Speech and Language, 35(4), 241–259. https://doi.org/10.1055/s-0034-1389097



50

49

## References

Thurm, A., Farmer, C., Salzman, E., Lord, C., & Bishop, S. (2019). State of the field: Differentiating intellectual disability from autism spectrum disorder. Frontiers in Psychiatry, 10, 526. https://doi.org/10.3389/fpsyt.2019.00526

Valicenti-McDernott, M., Tarshis, N., Schouls, M., Galdston, M., Hottinger, K., Seijo, R., Shulman, L., & Shinnar, S. (2013). Language differences between monolingual English and blingual English-Spanish young children with autism spectrum disorders. Journal of Child Neurology, 28(7), 45–948. https://doi.org/10.1177/088937812453204

World Health Organization. (2019, November 7). Autism spectrum disorders key facts. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders.

Zablotsky, B., Black, L. I., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bltsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. Pediatrics, 144(4), e20190811. https://doi.org/10.1362/peds.2019.63126.

Zuckerman, K. E., Mattox, K., Donelan, K., Batbayar, O., Baghaee, A., & Bethell, C. (2013). Pediatrician identification of Latino children at risk for autism spectrum disorder. Pediatrics, 132 (3), 445-483. doi: 10.1542/peds.2013-0383

