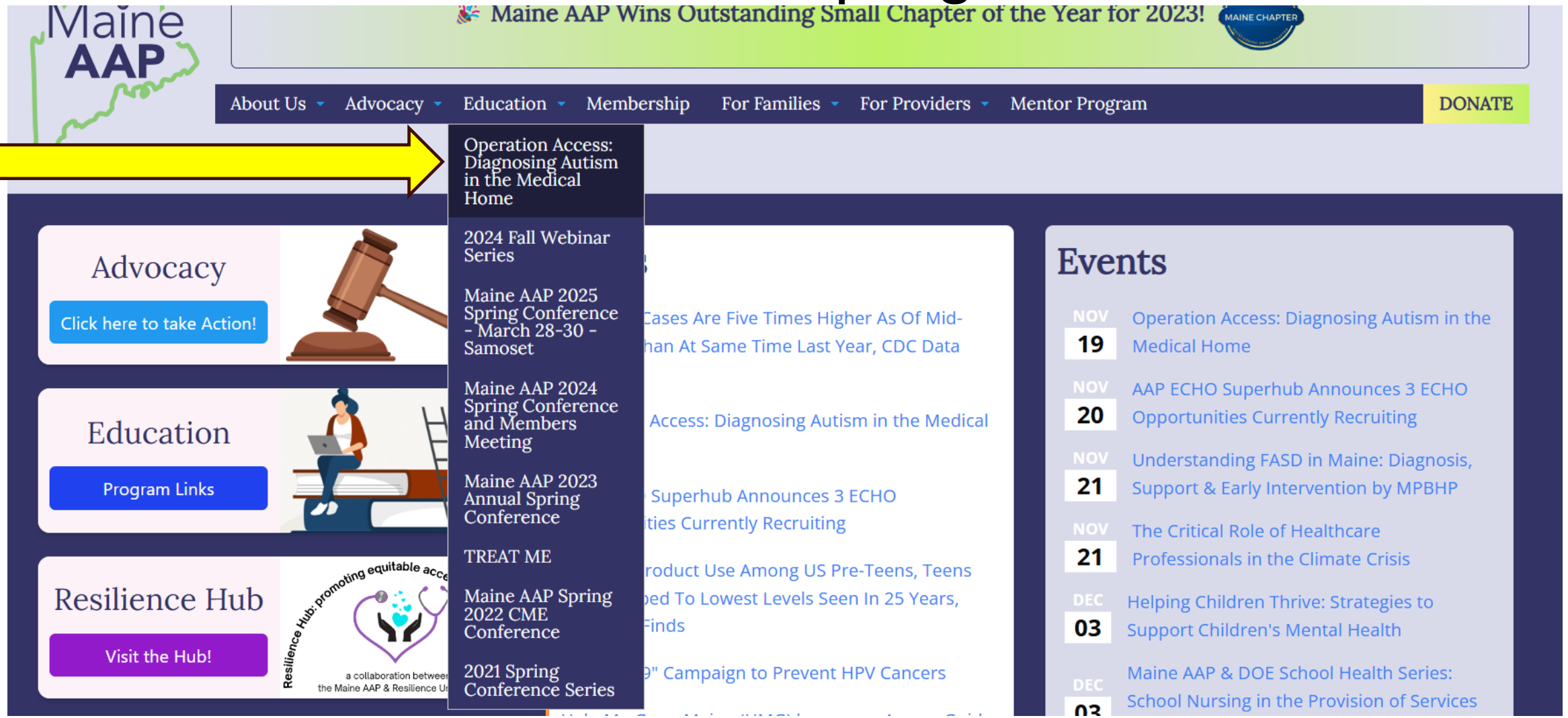
Operation Access: Diagnosing Autism in the Medical Home Learning Collaborative

Maineaap.org

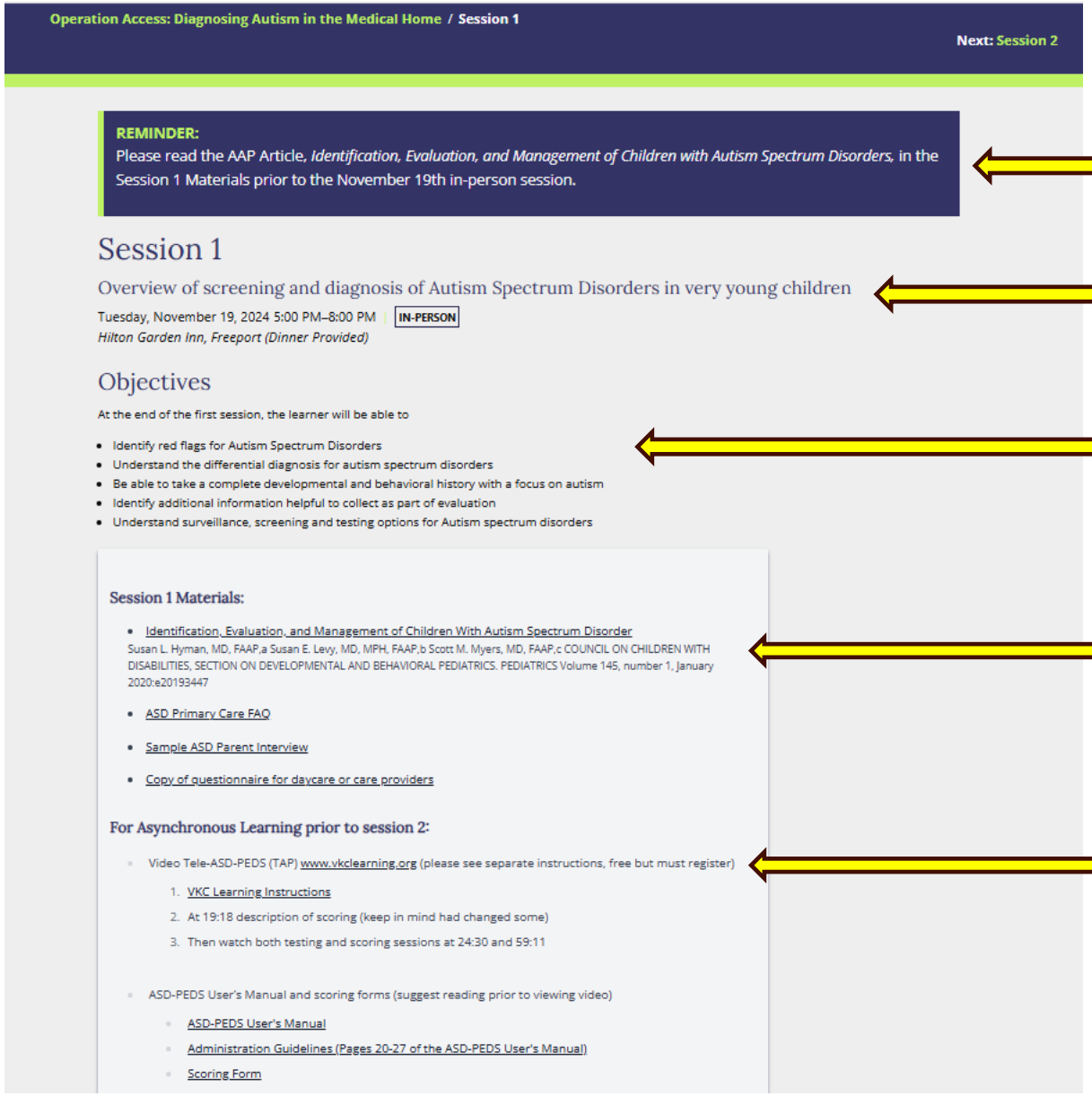


Under the Education tab, click on Operation Access: Diagnosing Autism in the Medical Home

- All 5 sessions and their objectives can be found on the main page. The session header will indicate the date, time & location of the event.

- Click on the individual sessions for the resources, recordings, and any asynchronous material that should be completed.

- The green section on the landing page will have any reminders for materials that should be read or completed before the live session. You can also find these reminders within the individual session pages.



- You will see any reminders at the top. Not all session will have reminders.
- Title, date, time, & location (in-person or zoom)
- Objectives
- Session Materials
- Any asynchronous learning that needs to be done prior to the next session will be at the bottom.

DIAGNOSING AUTISM SPECTRUM DISORDERS IN VERY YOUNG CHILDREN

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DEVELOPMENTAL- BEHAVIORAL PEDIATRICS
MAINEHEALTH MEDICAL GROUP – PEDIATRIC SPECIALTY CARE
ART BY JESSY PARK

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A department of Maine Medical Center

DISCLOSURES AND THANKS

- This project is funded by the Ellen Beaudin Fund through MaineHealth Barbara Bush children's Hospital with additional support from the Maine American Academy of Pediatrics and Maine DHHS Children's Behavioral Health

FIRST CASE

- Jesse is a 24-month-old girl who presents for her well visit. She has a history of several ear infections when she was younger but now has been healthy. Her parents are very concerned that she has a diagnosis of autism. The MCHAT screening is positive. They note that she often seems to "be in her own world." She does not usually respond to them when they try and engage her in play. She is fascinated by letters and numbers. She can match and identify them. She can say the letters of the alphabet but is not using other words. She often walks on her toes and flaps her hands. She is an extremely picky eater and also hates to have any mess on her hands. Noises such as the vacuum cleaner upset her to the point that they have to wait to vacuum when she is out of the house. She has a new baby brother and gets very upset when he cries. There is a family history of autism and family would like her diagnosed as quickly as possible so that she can get services. They are dismayed when you tell them that while you agree it appears she has autism it will have to be confirmed with a specialist and/or Child Development Services and that could take several months.

HOW DID WE GET HERE

- Change over time as what we recognize as autism and how we assess
- Desire to assure accurate in our diagnoses with some standardization (previously more informal observations and review of criteria)
- Developmental-Behavioral pediatrics recognized as own subspecialty (first exam 2002) only 700+ in US but became the "go to" for ASD
- A specialist driven diagnosis became the "key" to services – with access to specialists then specialists became the only ones that many believed could diagnose by many
- Lack of comfort in giving diagnosis even closely related specialties (varies by state, psychiatry, neurology)
- Primary care also under increasing pressure to see more patients, do more screening and handle more mental health concerns within the medical home

WHAT DO WE NEED?

- "A tiered model that streamlines risk classification and early intervention access for those children with clear phenotypic profiles of ASD may, by reducing need for comprehensive testing, simultaneously reduce wait times for those children whose complex presentations warrant additional evaluation. At present, however, most phenotypic presentations are funneled into the same model of care, regardless of provider capacity or family preference."

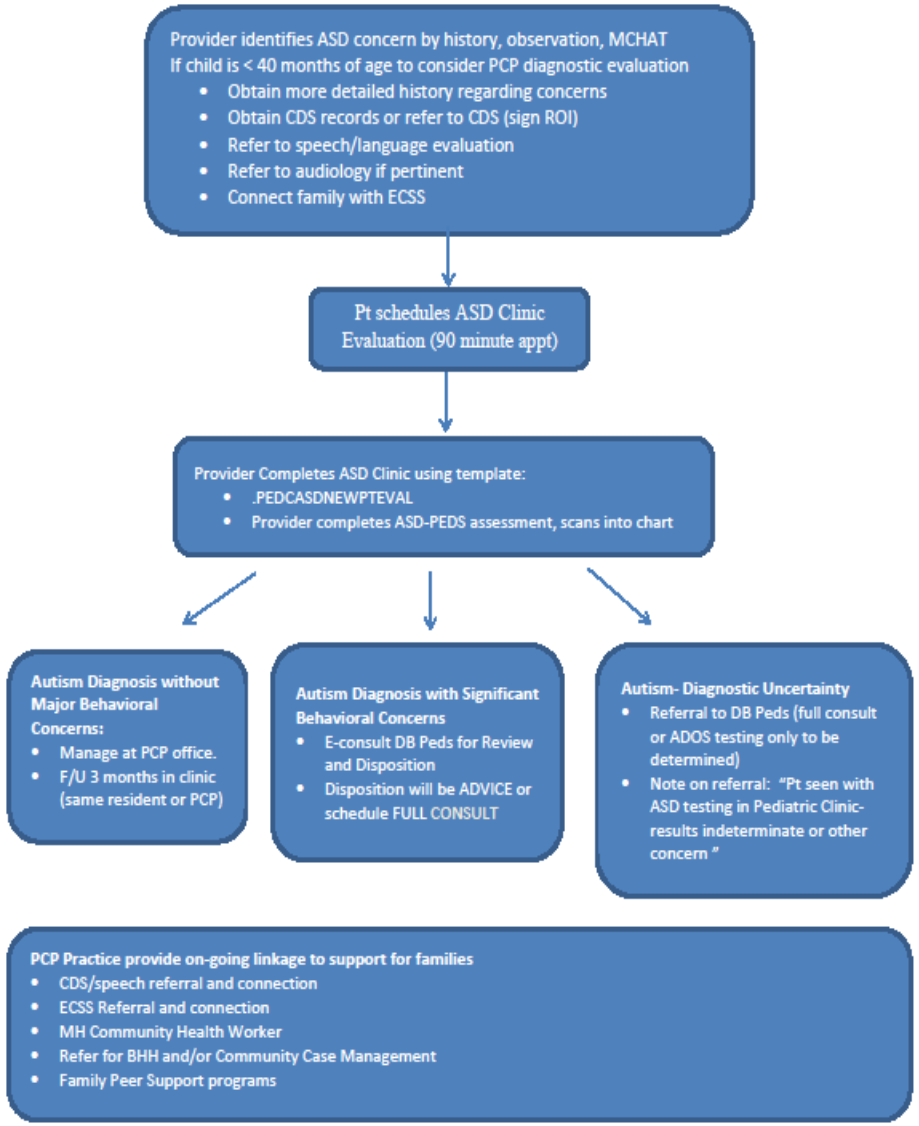
Reference

Corona, L.L., Wagner, L., Wade, J. et al. Toward Novel Tools for Autism Identification: Fusing Computational and Clinical Expertise. J Autism Dev Disord 51, 4003–4012 (2021). https://doi.org/10.1007/s10803-020-04857-x

OVERALL PROJECT GOALS

- For primary care providers to be able to diagnose very young children who have clear symptomatology with an autism spectrum disorder (ASD)
- For primary care providers to feel comfortable with the services and support available for families (and what to consider when they are not available)
- For primary care providers to increase their comfort level recognizing, diagnosing and managing common comorbidities of ASD
- Allowing increased capacity for more complex cases of ASD to be seen by DBPeds and others

Concern for Autism- Pediatric Clinic *draft Nov 2024*



GOALS FOR SESSION

- Reminder typical language and social emotional development
- Describe early signs that could indicate risk for ASD
- Be familiar with the DSM 5 diagnostic criteria for autism spectrum disorder (ASD)
- Be able to take a complete developmental and behavioral history with a focus on Autism
- Identify additional information helpful to collect as part of the evaluation
- Understand surveillance, screening tools and diagnostic instruments for ASD

**Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*

TYPICAL LANGUAGE SOCIAL & PLAY SKILLS DEVELOPMENT

REVISED
CDC DEVELOPMENTAL MILESTONE CHECKLISTS

- 12 free online CDC developmental surveillance milestone checklists
  - from 2 months to 5 years
  - help families learn more about how children play, learn, speak, act, and move
  - 15 and 30 months new checklist ages

https://www.cdc.gov/ncbddd/actearly/milestones/index.html

EVIDENCE-INFORMED MILESTONES FOR DEVELOPMENTAL SURVEILLANCE TOOLS

PEDIATRICS®

Articles

SPECIAL ARTICLES | FEBRUARY 08 2022

Evidence-Informed Milestones for Developmental Surveillance Tools

Jennifer M. Zubler, MD; Lisa D. Wiggins, PhD; Michelle M. Macias, MD; Toni M. Whitaker, MD; Judith S. Shaw, EdD, MPH, RN; Jane K. Squires, PhD; Julie A. Pajek, PhD; Rebecca B. Wolf, MA; Karnesha S. Slaughter, MPH; Amber S. Broughton, MPH; Krysta L. Gerndt, MPH; Bethany J. Mlodoch; Paul H. Lipkin, MD

Pediatrics March 2022; 149 (3): e2021052138. https://doi.org/10.1542/peds.2021-052138

- Goal is to avoid/decrease the "Wait and See" approach- based on when 75% achieve milestone
- Promote early detection by supporting screening as the next step
- Improve clarity and open lines of communication to share concerns
  - Missing a milestone should prompt communication and referral options

LANGUAGE DEVELOPMENT

- 2 months: sounds other than crying, reacts to loud sounds
- 4 months: cooing, makes sounds back when you "talk" to him, turns head to voice
- 6 months: takes turns making sounds with you, blows raspberries, squealing noises
- 9 months: babbling mamamama dadadada babababa
- 12 months: waves bye, uses mama dada more specifically, understands no (stops briefly)
- 15 months: one to two words besides mama and dada, looks at familiar object when named, directions with gesture, points to get help
- 18 months: 3 or more words, familiar directions without a gesture

LANGUAGE DEVELOPMENT

- 24 months: can point with "where's the…", 2 words together "more milk", points to 2 body parts, more gestures than pointing and waving
- 30 months: says at least 50 words, two-word phrases now with action word "doggie run", labels pictures, pronouns starting
- 36 months: conversation- at least twice back and forth, asks who, what, where and why, names actions, gives name, mostly understandable
- 4 years: sentences 4 or more words, says some words from song, story, nursery rhyme, can report an event
- 5 years: tells a story with at least two events (real or not), answers simple questions about a story, conversation now back and forth 3 or more times, uses or recognizes simple rhymes

KEY SOCIAL MILESTONES OVERVIEW

2 months

Social smile

4 months
Looks at you, moves, sounds to get attention

6 months
Knows familiar people, likes mirror

9 months
responds to name

12 months
Plays games like pat-a-cake

15 months
Copies peers, shows objects, hugs/ doll/toy
Shows affection

18 months
Points to show, moves away but checks that you are close by

24 months
Notices when others hurt or upset

30 months
Plays next to and sometimes with peers
"look at me"

36 months
Calms 10 min after you leave
Joins peers in play

https://www.cdc.gov/ncbddd/actearly/milestones/index.html

PLAY SKILLS MILESTONES

- At 24 months, most children:
  - Use objects symbolically
    - Use a crayon to pretend to give a baby a bottle, speak into a ball as a phone
  - Use toys as complete objects rather than becoming preoccupied with one part of the toy (whole vs. parts)
  - Are excited about the company of others
  - Imitate the behaviors of others

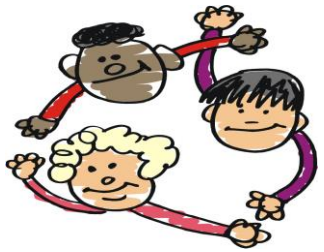
PLAY SKILLS MILESTONES CONT'D

- Most 3 year olds:
  - Notice other children and join them to play
  - Pretend to play different characters with you or talk for dolls or figurines

https://www.cdc.gov/ncbddd/actearly/milestones/milestones-3yr.html

- By 4 years, most children:
  - Pretend to be something else during play (teacher, superhero, dog)
  - Ask to go play with children if no other children are around

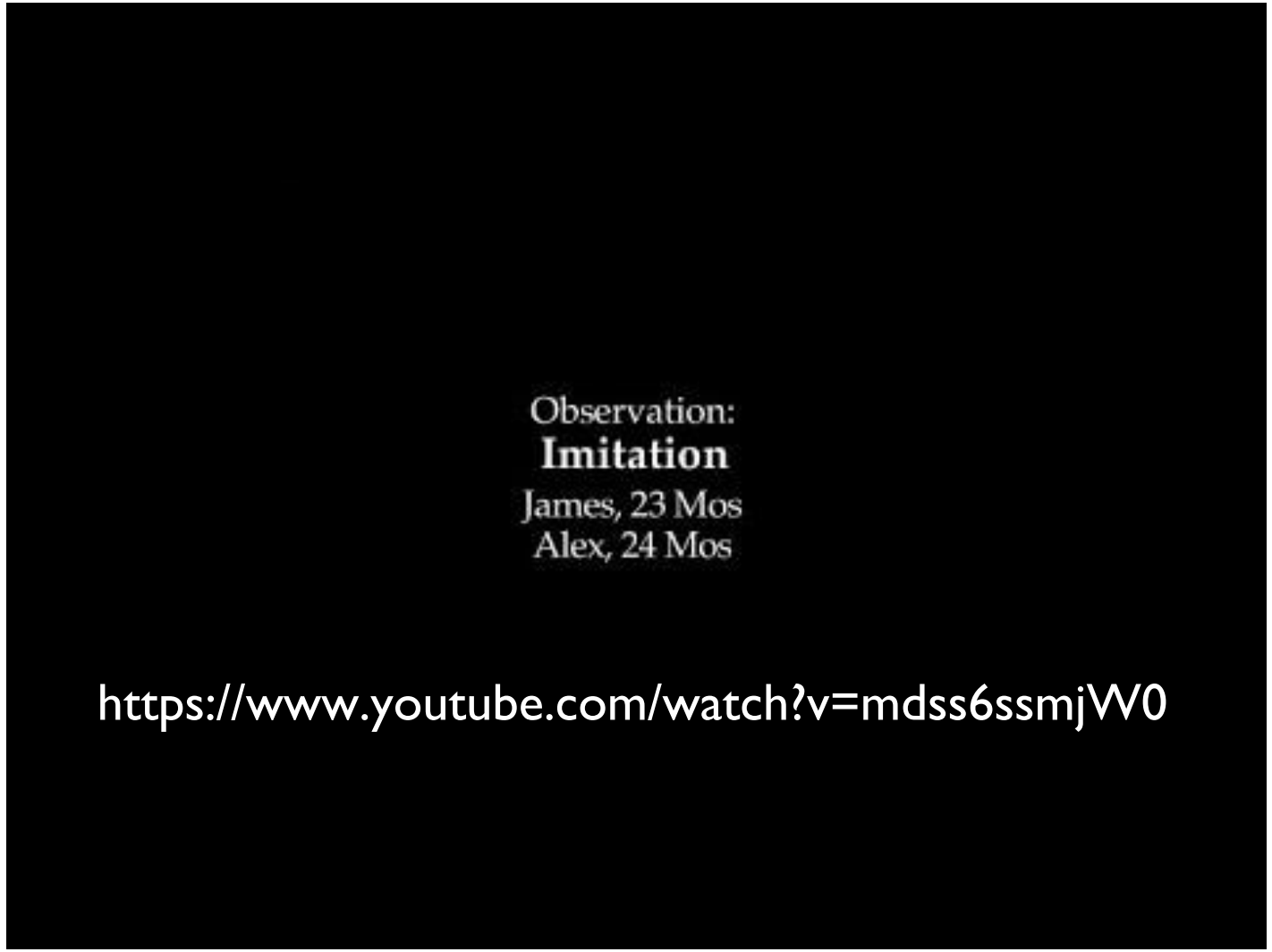
https://www.cdc.gov/ncbddd/actearly/milestones/milestones-4yr.html



RESPONSE TO NAME – 9 MONTHS

JOINT ATTENTION – 15 MONTHS

https://www.youtube.com/watch?v=yLBuoOWdOdE



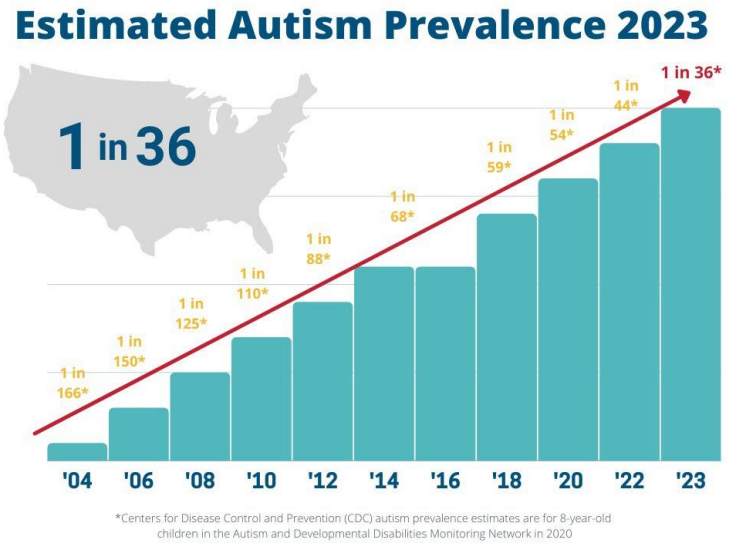
PARALLEL PLAY

https://www.youtube.com/watch?v=yAv0G6S5ZPc

SYMBOLIC PLAY

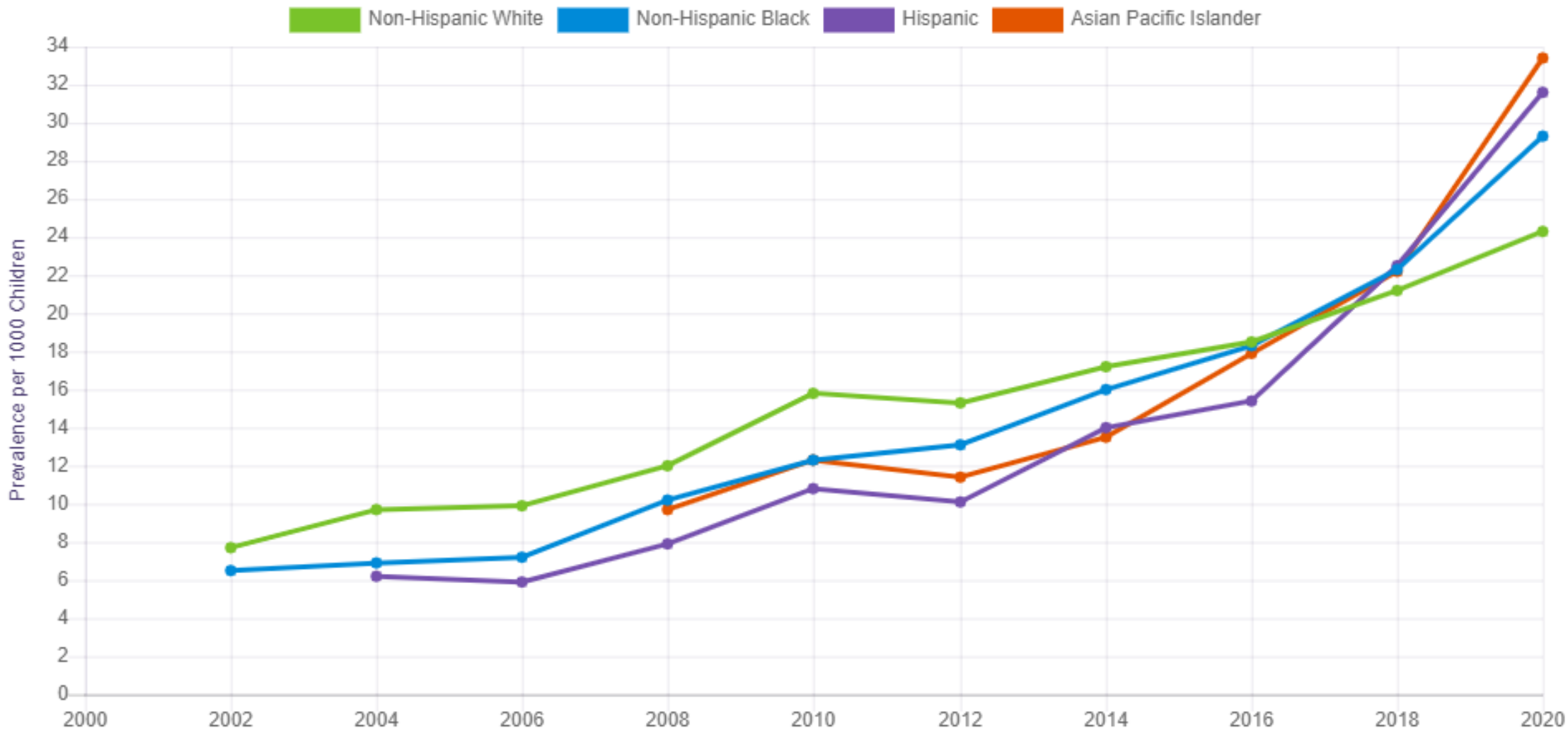
AUTISM SPECTRUM DISORDERS

- 1 in 36 people have Autism Spectrum Disorder
- Recognizable often prior to 2 yrs but median dx 4 yrs
- Autism is more likely to occur in boys than girls (although newer studies show numbers for girls increasing)
- Autism occurs across all races/ethnicities
- There is no medical test for autism
- There are over 100 autism risk genes identified
- Intervention yields best outcomes
- Increase in prevalence likely multifactorial

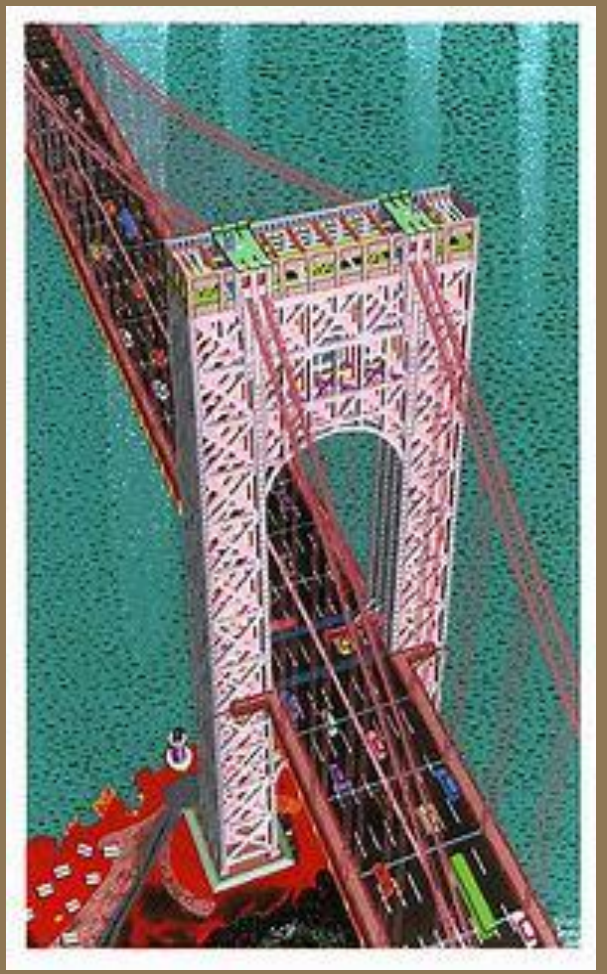


Prevalence Estimates by Race/Ethnicity

Show ADDM prevalence estimates* by race/ethnicity for: U.S. or Total† Apply



SO HOW DO WE START?



DEVELOPMENTAL SURVEILLANCE

- A longitudinal, collaborative process through which "health professionals and families observe the emergence of abilities in children over time."
- Components include obtaining a developmental and behavioral history, eliciting and attending to parents opinions, developmental questionnaires for parents, direct observation of the child, sharing concerns with other professionals, and the use of formal developmental screening instruments.

SCREENING

Early identification of ASD and appropriate referral for subsequent specialized developmental services greatly improves long-term outcomes for children with ASD

The American Academy of Pediatrics (AAP) recommends ongoing developmental surveillance at every visit

Developmental screening at 9, 18, and 24 or 30 months

Autism-specific screening at 18 and 24 months (MCHAT)

AUTISM SCREENING: MODIFIED CHECKLIST FOR AUTISM IN TODDLERS, REVISED WITH FOLLOW-UP: M-CHAT-R/F

- Purpose: screen for risk of ASD
- Validated developmental screening tool for toddlers between 16-30 months
- Designed to identify children who may benefit from a more thorough developmental and autism evaluation
- 20 yes/no questions administered to parents or guardians
- M-CHAT-R/F: Follow-up questions available, as needed (esp. if medium risk)
- Available online for FREE at: https://mchatscreen.com/

Next slide: Available in numerous languages at https://mchatscreen.com/mchat-rf/translations/

M-CHAT-R

LOW-RISK:	Score 0-2
MEDIUM-RISK:	Score 3-7 Administer Follow-Up for additional info
HIGH-RISK:	Score 8-20 Refer directly for further evaluation
M-CHAT-R Follow Up	Score ≥ 2 = positive screen Refer directly for further evaluation

M-CHAT-R LANGUAGE TRANSLATIONS

- Available in numerous (38) languages
  - Some with pictures at https://mchatscreen.com/mchat-rf/translations/

6. ¿Su hijo/a señala con un dedo cuando quiere pedir algo o pedir ayuda?

7. ¿Su hijo/a señala con un dedo cuando quiere mostrarle algo interesante?

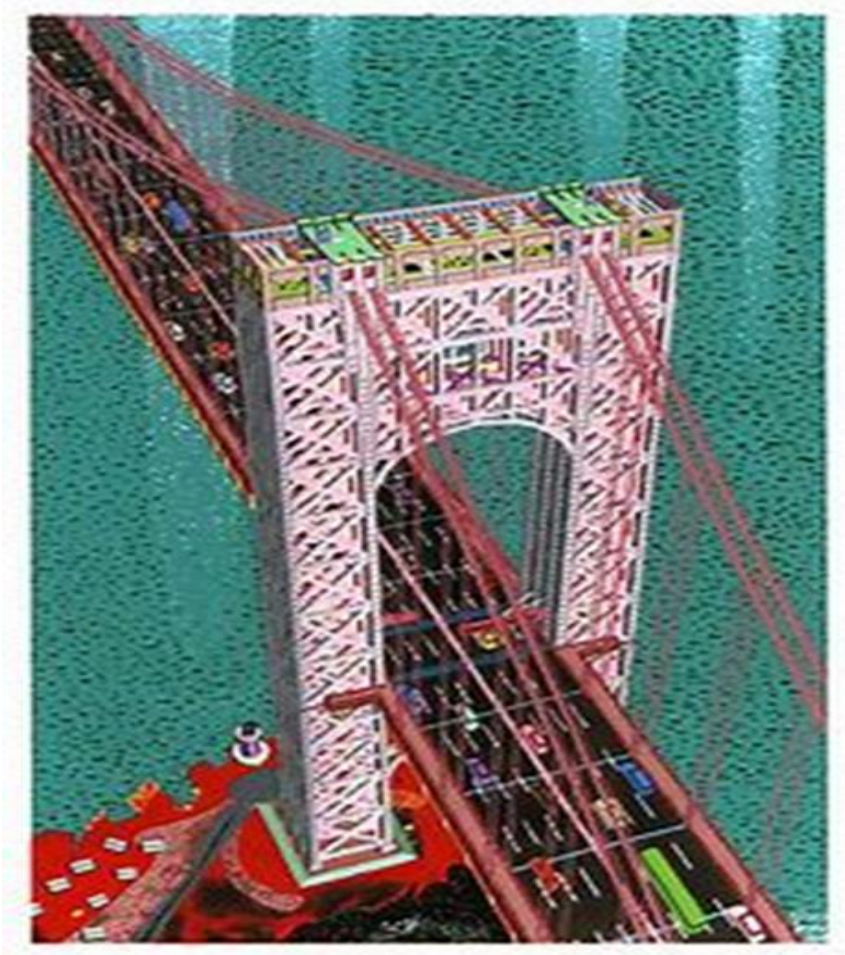
1

2

POSITIVE SCREEN → TAKE ACTION

Multipronged approach

- Review screening results with the parents
- Referral to audiologist (speech delay)
- Vision Screening- esp if possible related behaviors
- Referral to qualified autism diagnostician- yourself! Your clinic!
- Referral to community resources
  - Child Development Services (CDS) Part C up to 36 months (now called Early Intervention for ME)
  - CDS Part B (3-5 year olds)
  - Local school if kindergarten eligible
  - Clinic based speech and occupational therapy
  - Parenting Support
  - If already in services get the records!!



SECOND CASE

- Taylor is a 24-month-old boy who presents for his well visit. While he has been healthy, he is still not saying any words. His parents thought he might have had a few words when he was younger but he has stopped saying those. They describe him as being very independent and very smart. When he wants something, he will either get it himself or lead his parents to it. He does not respond consistently to his name. He is fascinated with anything with wheels and loves to figure out how things work. His favorite thing to do is line up his construction vehicles in a row. He will often lie down and study them and spin the wheels. He has brought two with him today and wanders around the office with one in each hand. At one point he puts them on the ground, spins the wheels and flaps his hands as he studies them. You strongly suspect autism. You glance at the MCHAT that his mother has filled out and it does not appear to be positive. You start to discuss your concerns with her, and she notes that she is not really worried, her older son and Taylor's father were late to talk and "they are fine now." You suggest a referral to Child Development Services and the family declines saying that they want to just monitor for now.

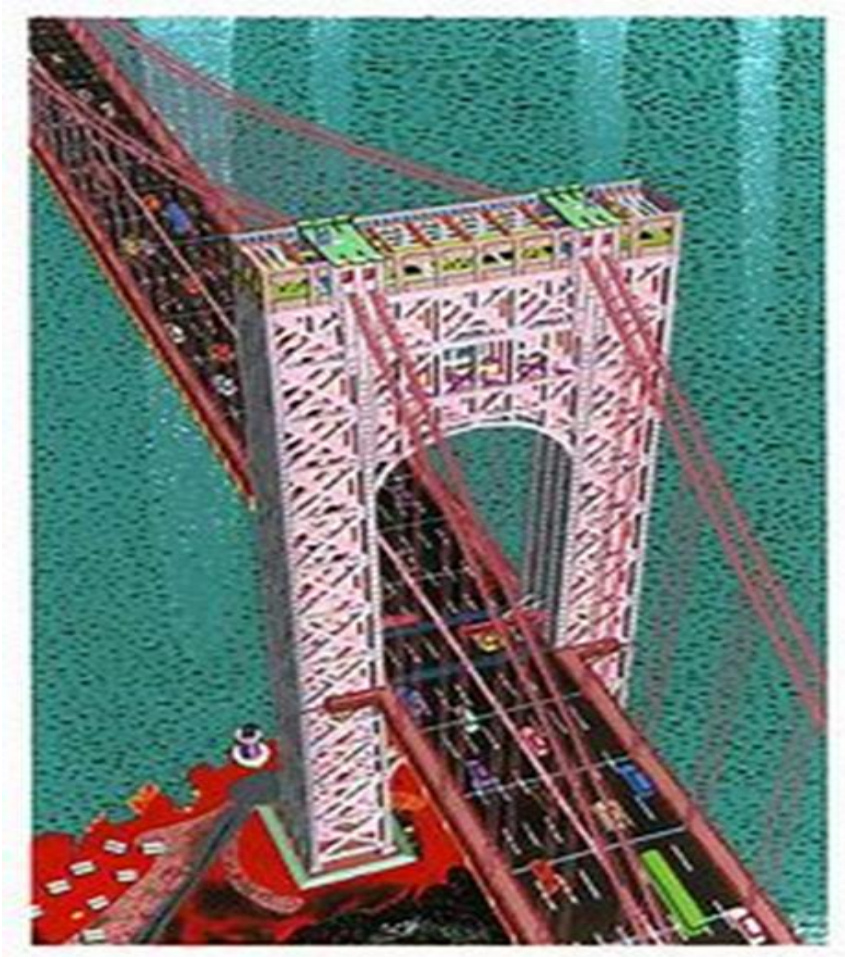
THIRD CASE

- Ahmed is a 36-month-old boy who presents to clinic for his well visit. Ahmed lives in a home that is primarily Arabic speaking but goes to daycare in an English-speaking center. Parents are concerned about his speech. They report that he is not yet using any words in either language. He had a tongue tie when he was younger, and they are concerned this is the cause of his current challenges. The daycare center had encouraged the family to seek out services with CDS and had a case manager that assisted them with that process but the family reports that they were only coming to the home once every other week and now that he is three, they stopped coming and they have no services. A review of the chart indicates that they were referred to speech at his 24-month-old well visit but family reports that they "have not heard from them." In the room, he is very self directed and active. He wants to play with the computer and is upset that he cannot press the buttons. He has only brief occasional eye contact and does not respond to his name. He smiles when his mother holds him upside down on his lap. Several times during the visit he pulls on his father's hand trying to lead him to the door.

NEGATIVE SCREEN BUT CLEAR CONCERN → TAKE ACTION (AFTER A DELICATE CONVERSATION)

Multipronged approach

- Review screening results with the parents
- Referral to audiologist (speech delay)
- Vision Screening- esp if possible related behaviors
- Referral to qualified autism diagnostician- yourself! Your clinic!
- Referral to community resources
  - Child Development Services (CDS) Part C up to 36 months (now called Early Intervention for ME)
  - CDS Part B (3-5 year olds)
  - Local school if kindergarten eligible
  - Clinic based speech and occupational therapy
  - Parenting Support
  - If already in services get the records!!



ADDITIONAL LEVEL I SCREENERS (FREE)

- The Survey of Well-being of young children (SWYC) Parent's observations of Social Interactions (POSI) 16-35 months sens 88.5 % spec 56.9%
- Communication and Symbolic Behavior Scales Developmental Profile- Infant/Toddler checklist (CSBS-ITC) 6-24 months sens 0.78 spec 0.84 – does not discriminate between ASD and language delay
- Social Communication Questionnaire (SCQ) 4 years plus (child must have mental age 24 months) sens 0.85, spec 0.75

CAVEAT…

- No screening measure is 100% sensitive and specific
- If screening low risk, parents have no concerns, and you have no concerns likely ok
- If screening low risk, parents have no concerns, but you are concerned likely needs additional evaluation and this becomes a challenging but important conversation (would we wait with asthma?)
- If screening low risk, parents have significant concerns, but you do not witness the concerning behaviors then still likely needs further evaluation
- If screening high risk, parents have significant concerns and so do you- you know what to do!

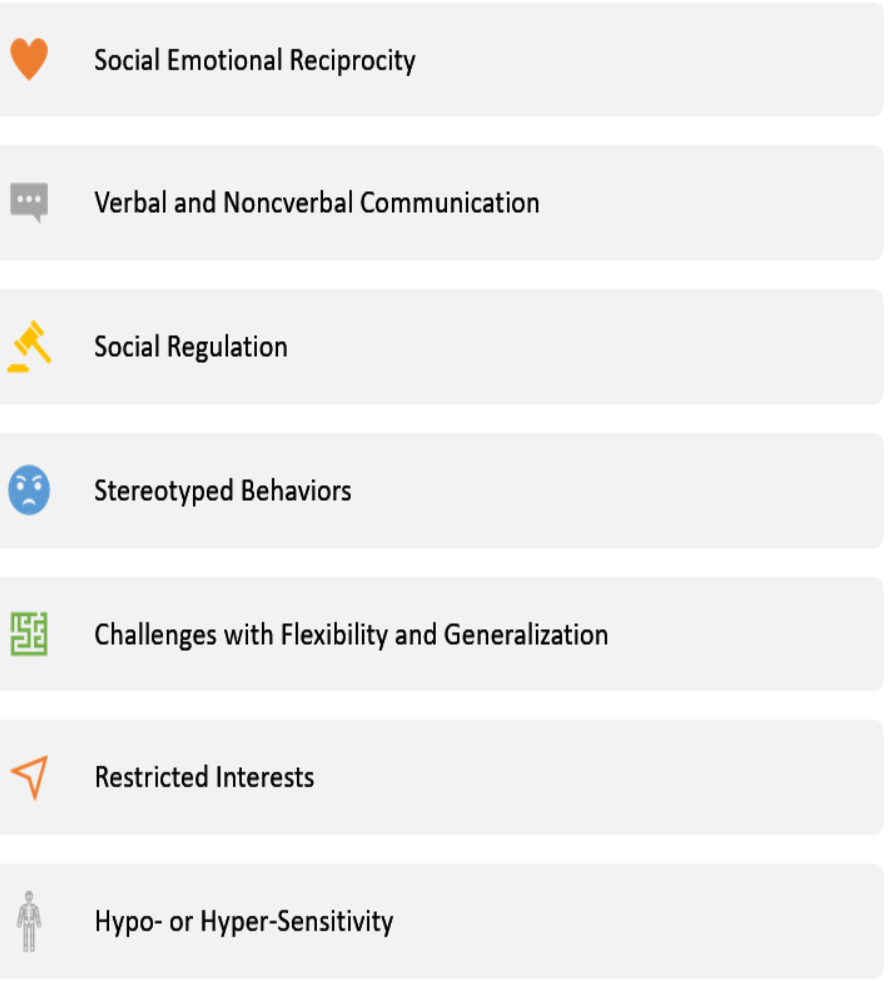
A NOTE ABOUT REGRESSION OF DEVELOPMENT OR BEHAVIOR

- Developmental or behavioral regression should always be taken seriously
- Describes a significant loss of previously acquired milestones or skills
- When regression occurs in association with ASD, motor skills generally preserved
- Occurs in minority of children with ASD
- Mean age of parental report is 20 months
- Most frequently report is **loss of language**, followed by loss of social-emotional connectedness
- Theories of regression- synaptic "over pruning" and or response to genetic factors
- If regression more significant and ongoing then needs referral to neurology and likely genetics

THE DIAGNOSTIC PROCESS: A NEW FRONTIER

DIAGNOSTIC AUTISM SPECTRUM DISORDER EVALUATION: CONSIDERATIONS

- Typical behaviors that have not developed
- Atypical behaviors that are not usually present
- No single behavior that is always indicative of autism, nor is there any one specific behavior that would exclude children from an ASD diagnosis
- Examine strengths and areas of need
- Symptom severity varies and can change over time
- Some symptoms manifest themselves more strongly as a child ages and social expectations increases
- Child, family, cultural, and linguistic considerations



DIAGNOSTIC EVALUATION: MULTI-MODAL ASD ASSESSMENT IN A PERFECT WORLD WITH NO TIME AND RESOURCE CONSTRAINTS

- Record Review
- Interviews
- Information from caregivers/therapists outside the home- teacher/daycare provider/therapist questionnaires
- Observations (clinic, home, school, social/community/playgrounds)
- Vision and hearing screening/testing
- Speech and language testing and other previous evaluations

- Rating Scales
  - General behavior
  - Autism-specific rating scales
  - Adaptive functioning measures
- Direct Testing / Structured Observations such as…
  - Autism Diagnostic Observation Schedule-Second Edition (ADOS-2)
  - TeleASD Peds/ASD-PEDS
  - CARS-2

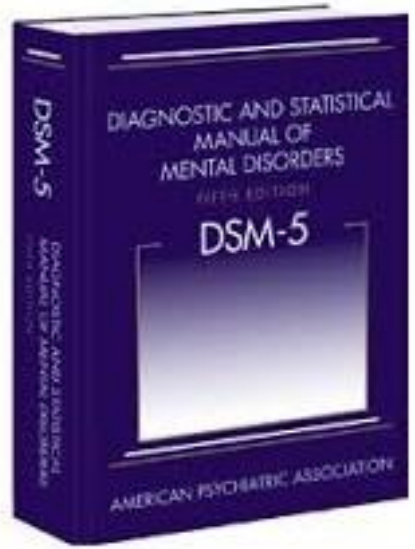
Reports of the child's functioning in various contexts (such as home and school)

And now the criteria

DSM 5 CRITERIA FOR ASD DIAGNOSIS

Social Interaction & Communication Difficulties

- Deficits or delays ***3 out of 3*** of the following:
  1. Social-emotional reciprocity
  2. Nonverbal communication
  3. Relationships with others



**Symptoms can be present by history*

Restricted Interests & Repetitive Behaviors

- Must exhibit ***at least 2 out of 4*** of the following:
  1. Repetitive motor movements, speech, or use of objects
  2. Need for sameness / routine
  3. Fixated interests or obsessions
  4. Hyper / hypo – reactivity to sensory input, or interest in sensory exploration

ASD LEVELS PER DSM 5

Level 3 "Requiring very substantial support"

Severe deficits in verbal and nonverbal social communication, minimal response to social overtures, inflexibility, stereotypical behaviors and/or repetitive behaviors markedly interfere

Level 2 "Requiring substantial support"

Marked deficits in verbal and nonverbal social communication, limited initiation, markedly odd nonverbal communication, inflexibility or restricted/repetitive behaviors still obvious to the casual observer

Level 1 "Requiring support"

Without supports deficits in social communication cause noticeable impairments, difficulty with back and forth when not preferred interest, inflexibility interferes in one or more context

THE INTERVIEW

- Think of it has building a case
- Start with family concerns
- Templates are helpful but lists that are long can take a long time- use as guide but do not have to do verbatim
- Ask questions to clarify and affirm what you are observing in the office
  - "I noticed that Ahmed is flapping his hands when he is excited. Is that something you see a lot at home?"
  - I notice that it is very hard to get Taylor's attention, have you noticed that at home?
- Fill in other criteria that may not have been touched upon by utilizing template
- Have some basic toys in the room (not the testing ones you will be using) to keep busy and be able to observe more while talking

DIFFICULTIES IN SOCIAL EMOTIONAL RECIPROCITY, INCLUDING TROUBLE WITH SOCIAL APPROACH, BACK AND FORTH CONVERSATION, SHARING INTERESTS WITH OTHERS, AND EXPRESSING/UNDERSTANDING EMOTIONS.

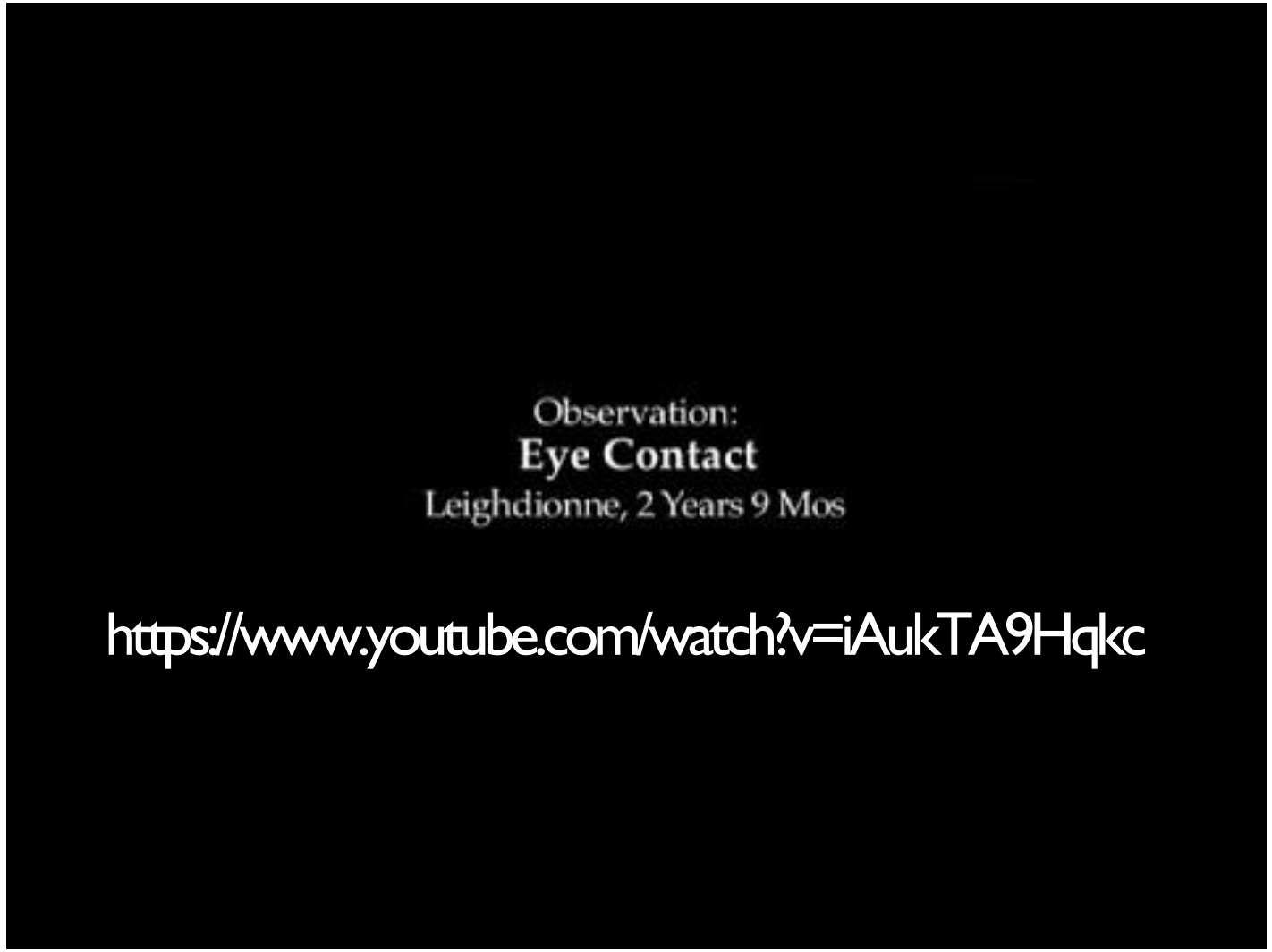
- Uses others as tools (putting parents' hand on something to make it work)
- Not responding to name consistently
- Does not initiate conversation or interaction
- Lack of showing, bringing, pointing out objects of interest to others
- Failure to share enjoyment, excitement or achievement
- Impaired joint attention
- Lack of responsive social smile
- Does not show pleasure in social interactions
- Only initiates to get help typically
- Indifference or aversion to physical contact or affections (often tricky in interpretation, can be sensory in nature)

DIFFICULTIES IN NONVERBAL COMMUNICATION USED FOR SOCIAL INTERACTION INCLUDING ABNORMAL EYE-CONTACT AND BODY LANGUAGE AND DIFFICULTY WITH UNDERSTANDING THE USE OF NONVERBAL COMMUNICATION LIKE FACIAL EXPRESSIONS OR GESTURES FOR COMMUNICATION.

- Impairments in the social use of eye contact
- Impairments in use and understanding of gestures (pointing, waving)
- Limited or exaggerated facial expressions
- Lack of warm, joyful expressions directed at others
- Inability to recognize or interpret other's nonverbal expressions, gestures
- Lack of coordinated verbal and nonverbal communication (eye contact with words)
- Lack of coordination of non-verbal communication (eye contact with gestures)

DEFICITS IN DEVELOPING AND MAINTAINING RELATIONSHIPS WITH OTHER PEOPLE (OTHER THAN WITH CAREGIVERS), INCLUDING LACK OF INTEREST IN OTHERS, DIFFICULTIES RESPONDING TO DIFFERENT SOCIAL CONTEXTS, AND DIFFICULTIES IN SHARING IMAGINATIVE PLAY WITH OTHERS

- Play behind what would be expected for age- ex still parallel when should be cooperative
- Lack of interest in engaging with peers
- Does not respond to social approaches from other children
- Acts as if they are "in their own world"
- Only tends to engage with others when more sensory type play
- Prefers to play on own and does not want others in space
- Lack of response to contextual cues (hard to discern in younger children)
- May have interest in other children but approach to interact with them is not age appropriate



DECREASED EYE CONTACT & RESPONSE TO NAME

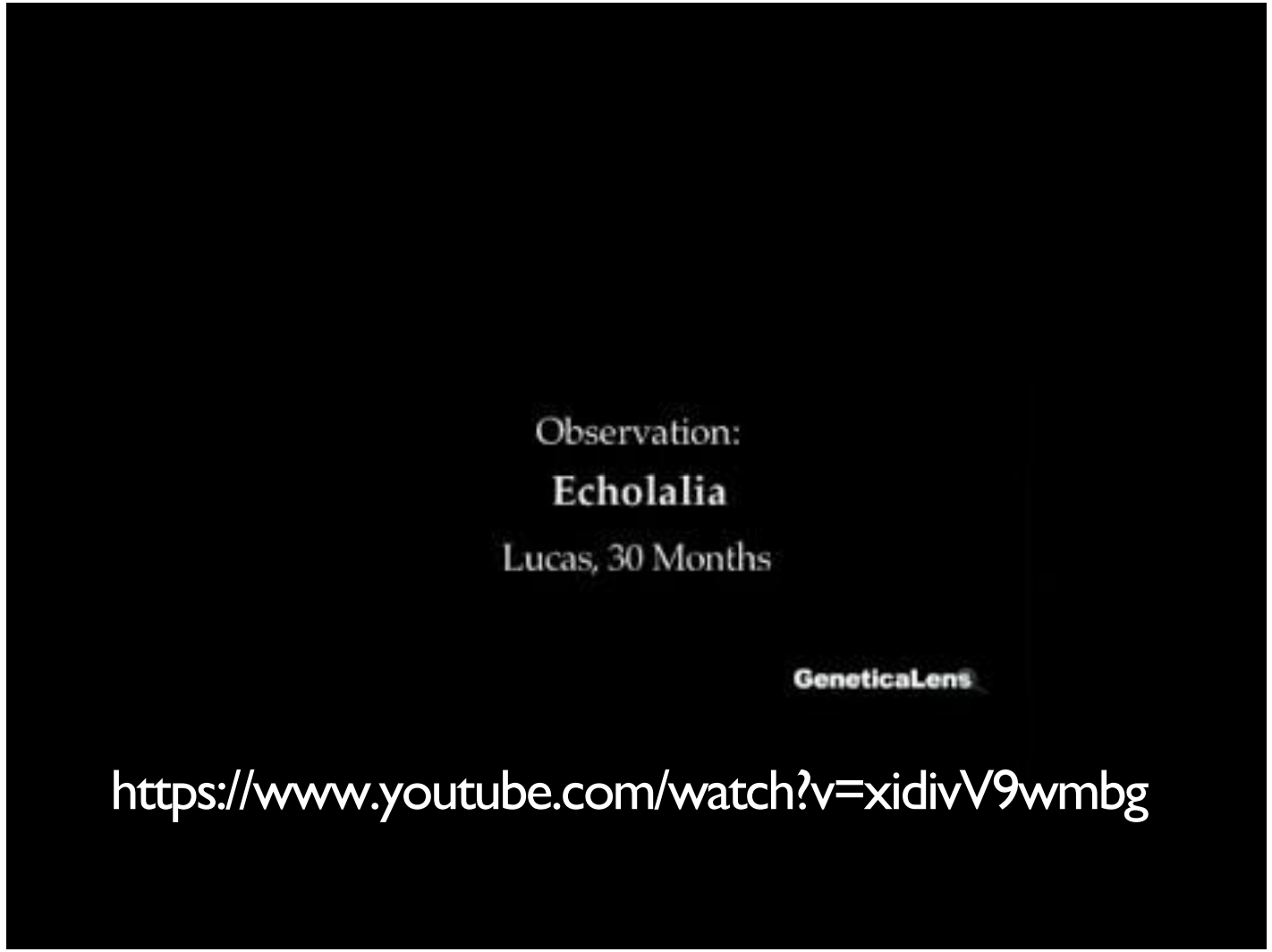
https://www.youtube.com/watch?v=1Q2CzTJh7nI&t=6s

COMPARING PLAY SKILLS, JOINT ATTENTION, SOCIAL ENGAGEMENT

STEREOTYPED SPEECH, REPETITIVE MOTOR MOVEMENTS, ECHOLALIA (REPEATING WORDS OR PHRASES, SOMETIMES FROM TELEVISION SHOWS OR FROM OTHER PEOPLE), AND REPETITIVE USE OF OBJECTS OR ABNORMAL PHRASES.

- Echolalia- delayed or immediate- need to discern from the copy back that shows learning language
- Repetitive sounds such as digga digga digga, humming
- Jargon beyond the age that would be expected and not in conversational way
- Repetitive hand movements
- Toe walking
- Intense body tensing
- Unusual facial grimacing, excessive teeth grinding
- Repetitively puts hands over ears (also could be sensory)
- Repetitive play
- Nonfunctional play (spinning wheels of a car)
- Lining up toys/objects
- Repetitively opening and closing doors, turning lights on and off

REPETITIVE VOCALIZATIONS



https://www.youtube.com/watch?v=xidivV9wmbg

RIGID ADHERENCE TO ROUTINES, RITUALIZED PATTERNS OF VERBAL OR NONVERBAL BEHAVIORS, AND EXTREME RESISTANCE TO CHANGE

- Specific, unusual multiple step sequences of behaviors
- Insistence on rigidly following specific routines (bedtime may or may not be exception to this depending…)
- Repetitive questioning on about a particular topic- asking the same question even though answered often
- Verbal rituals- requiring others to answer back in a certain way
- Difficulty with transitions beyond what is expected for developmental level
- Overreaction to alternate route or different person driving car
- Rule bound

HIGHLY RESTRICTED INTERESTS WITH ABNORMAL INTENSITY OR FOCUS, SUCH AS A STRONG ATTACHMENT TO UNUSUAL OBJECTS OR OBSESSIONS WITH CERTAIN INTERESTS

- Interests that are abnormal in intensity
- Preoccupations/obsessions
- Attachment to unusual inanimate objects (carrying around things like utensils, string, hard objects)
- Narrow range of interests
- Focused on the same few objects, topics or activities
- Preoccupation with numbers, letters or symbols
- Excessive focus on nonrelelvant or nonfunctional parts of objects- note door stopper or other small features in room they fixate on

HYPER- OR HYPOREACTIVITY TO SENSORY INPUT OR UNUSUAL INTEREST IN SENSORY ASPECTS OF THE ENVIRONMENT

- High tolerance to pain
- Indifference to temperature
- Poking own eyes
- Preoccupation with texture or touch (attraction or aversion)
- Unusual visual exploration, close inspection of objects for no clear purpose
- Looks at objects out of corner of eye
- Unusual squinting of eyes
- Fascination watching things spin
- Odd response to sensory input (extreme distress to atypical sound)
- Atypical/persistent focus on sensory input (sound, smell, taste, vestibular- loving to be upside down) visual
- Licking or sniffing of objects

GATHERING ADDITIONAL INFORMATION

- Information from other sources can be very helpful- especially when family or others feel that there are not concerns
- Information from treating therapists
- Information from daycare or other care providers (sample questionnaire on collaborative website)
- Any testing that may have already occurred
- Records form Child Development Services (always get release signed as soon as possible in process, CDS requires their own release, working on getting CDS to automatically send to PCP)

EVALUATION TOOLS

THE AUTISM DIAGNOSTIC OBSERVATION SCHEDULE – SECOND EDITION (ADOS-2)

- Direct Testing
- The ADOS-2 is a semi-structured, standardized assessment of:
  - communication,
  - social interaction,
  - play,
  - and restricted and repetitive behaviors.
- Results can be used to inform diagnosis, intervention, treatment planning, and educational placement
- Too many considered the "gold standard" and that has not helped access
- Cost $2695 plus toddler kit $839 plus $ 9 per scoring form

TESTING AND LEVEL 2 SCREENING OPTIONS

Test name	Ages appropriate for	Time to administer	Type test	Other notes	Cost
RITA-t	18-36 mos	About 20 minutes	Level 2 screener Hands on	7 item kit, scarf would be hard to wash	Kit 65, 4 hour online training 175
Tele-ASD –Peds now ASD-PEDS	18-36 mos	10-20 minutes	Diagnostic Hands on, includes parent	Indicates for use with autism diagnostic experience , can be done remotely, has online teaching but not formal	Free Dowloadable scoring sheets Can make up kit on own for $25-50
STAT: Screening Test for Autism in Toddlers	24-36 mos (can be extended 14-48 mos)	12 items, need set kit, 20 minutes	Level 2 Screener but used for diagnosis Hands on	2 day training to teach STAT-MD model Plush toys, hard to clean	Have to buy kit, optimal if attend training Kit 520 and test protocols 25 for 25 and user's manual 25
Childhood Autism Rating tool (CARS 2)	24 months and older	10 minutes (although more complex than that as form itself is lengthy and includes history)	Diagnostic- based on history and observations	No kit for this but some toys could be helpful for observation	Online training 85, manual 142 Standard version forms 76 for pack 25, questionnaires for parents 55 for pack 25

WHY USE A TOOL AT ALL IF YOU JUST "KNOW"?

- Helpful in describing the symptoms of an autism spectrum disorder that you are actually seeing
- Allows child to "show what they know" – remember you are in a medical setting and the initial behaviors you see may not be as telling
- Opportunity to bring out behavior you might not otherwise see (stim toys wamke some things clearer)
- Allows you to be able to assist family with acceptance of diagnosis (I noticed that…)
- It is generally the expectation of Child Development Services and DOE that a tool is used as part of a diagnostic evaluation

WEBSITES FOR TESTING OPTIONS

- Information about STAT-MD training https://vkclearning.org
- Information about Tele-ASD-Peds and ASD PEDS https://vkclearning.org
- Information on RITA-T https://www.childrenshospital.org/research/labs/rita-t-research

- Information on CARS https://www.wpspublish.com/cars-2-childhood-autism-rating-scale-second-edition.html

HISTORY ASD-PEDS

- Prior to the pandemic Vanderbilt University studying ways to assist with diagnosis in a rural state-small pilot 2009 with training 5 PCPs to do MCHAT, interview and STAT, followed up with ADOS evaluation at center, 74% concordance
- 2014 expanded regional training to 27 providers over 3.5 years, agreement increased to 86-93%
- 2019 work being done to develop and test the Tele-ASD-PEDS which used machine learning to identify key behaviors that could be used to create tool
- In early 2020 was still in validation stage when pandemic set in and so pivoted use of the tool to assist with evaluations that now largely had to be done by telehealth
- Over time adjusted for in office use but still with directions to parents
- Newest version with instructions for clinicians to use directly with parent assist, designed to be flexible
- Hine, J., Foster, T., Wagner, L., Corona, L., Nicholson, A., Stone, C., Swanson, A., Wade, J., Weitlauf, A., & Warren, Z. (2023). ASD-PEDS: An Autism Evaluation Tool for Toddlers and Young Children. Vanderbilt University Medical Center. triad.vumc.org/asd-ped

KITS FOR ASD PEDS

- Play materials
  - Sensory toys, pretend play (doll, mini figures), plastic cup and spoon, shape sorter, blocks, musical toy
- Requesting material
  - Clear container with lid that closes tightly, preferred item for container (food, sticker, car)
- Ready set go materials
  - Ball, pop rocket, pull back car, deflated balloon, flying disc launcher

AUTISM SPECTRUM DISORDER ASSESSMENT IN TODDLERS (ASD-PEDS)

- Socially directed speech and sounds
- Frequent and flexible eye contact
- Unusual Vocalizations
- Unusual or repetitive play
- Unusual or repetitive body movements
- Combines gestures, eye contact, and speech/vocalization
- Unusual sensory exploration or reaction

*Designed for use with children under 36 months of age with limited language

GIVING THE DIAGNOSIS

- May want to consider a second visit to deliver diagnosis depending on time and family readiness
- We sometimes utilize telehealth- more often additional parents/caregivers can be present and while child must be present for at least part of the visit, can then be playing with preferred toys at home instead of racing around exam room- you know the families best and what would work for them
- Review each criteria briefly and note which aspect of the evaluation points to meeting each one
- Discuss the basics of recommended interventions, services and resources – know that this will have to be reviewed again at future visit (possibility of workshop given by our division being developed that will be open to your patients after pilot complete)
- Send hard copies of notes to family and Child Development Services with release ideally

RESPONSES TO DIAGNOSIS- BE PREPARED TO DISCUSS EACH

- Autism is only in this country- we don't have this in my country
- I did not speak a single word until I was 5 and I am fine
- His sister speaks for him- that is what he does not talk
- This is because of vaccines
- It is God's will- she will talk when she is ready.
- It is because she is hearing two languages at home
- He does not play with other kids because he has not been in school- as soon as he starts school he will interact with them
- She smiles at me and looks at me so she cannot have autism
- He is smart so he cannot have autism – he knows all his letters and is reading words!
- I think a different diet would help my child
- Will my child talk? When will my child talk?

WHERE DID IT COME FROM?

RISK FACTORS

Genetics

Sibling or close family member with ASD

Associated Conditions:

Developmental disorder

Psychiatric diagnosis

Neurological disorder

Chromosomal condition or genetic diagnosis

Environmental

Older parents

Prematurity & low birth weight

Birth complications

In utero exposure to valproic acid or thalidomide and others

?

NEUROBIOLOGY

- Differences in the way the brain looks and works
  - Atypical neural connectivity
  - Early brain overgrowth
  - Different gene expression patterns in the brain
  - Potential immune dysfunction factors
  - Neurotransmitter system differences
    - Serotonin (mood stabilizing)
    - GABA (inhibitory control)

GENETICS EVALUATION

- At this time given that most insurance require that patients receive genetic counseling prior to genetic testing being performed, best route is for referral to genetics – generally fragile X testing and autism/ID panel ordered unless clear dysmorphic features or history that leads in another direction
- Advantages if genetic cause identified
  - More information about prognosis/clinical course
  - Identifying and or treating medical conditions associated with the genotype
  - Can lead to having condition-specific family support
  - Avoiding therapeutic interventions that do not have evidence base
  - Access to emerging etiology specific treatments, research protocols
  - Avoiding additional expensive diagnostic tests

PROGNOSIS

Increased functioning / independence when:

- Diagnosis & treatment at young age
  - Cost of lifelong care can be reduced by 2/3 with early diagnosis & intervention- although debate about how much therapy is truly needed
- Higher intelligence (IQ) and adaptive skills
- Communicative phrase speech
- More social interest

INTERVENTIONS IN BRIEF

CHILD DEVELOPMENT SERVICES PART C

- Part C (think C for crib) covers children birth to 36 months
- CDS set up regionally
- Child typically assessed in the home using the Batelle
- if qualifies for CDS services then Individual Family Service Plan (IFSP) written
- Uses primary service provider model- so services tend to be limited- focus on training the parent to assist the child's development
- If an autism spectrum disorder is suspected then they should be referring for further evaluation, we are finding this is not happening consistently
- If autism spectrum disorder diagnosed should change intensity of focus of therapy but again we are not finding that this is consistently the case
- If receiving services as a toddler with IFSP then should be starting transition process at around 33 months to Part B of CDS at 36 months

CHILD DEVELOPMENT SERVICES PART B

- Age 36 months to starting kindergarten
- If received part C then should have been transitioned to Part B- parents need to understand that
- Often have updated evaluation as part of that transition
- If referred after age 36 months then will often need more extensive evaluation, again if autism suspected they should be referring for that evaluation but it is not consistently occurring – evaluation should include at least psychological, speech and language testing and occupational therapy evaluation
- If qualify for services the Individual Education Plan written – hope is for child to receive specially designed instruction (could be in special purpose preschool or mainstream setting), speech and language therapy and occupational therapy if needed.

INTERVENTIONS

- Several evidenced based interventions available
- Interventions may:
  - Reduce symptoms (that are truly interfering)
  - Improve cognitive ability and daily living skills
  - Maximize the ability of the child to function and participate in the community – have to remember our own bias in this
- Treatment plans are usually multidisciplinary, may involve parent-mediated interventions, and target the child's individual needs
- Often Applied Behavioral Analysis based – should recognize that this is controversial for some but comes in many forms

INTERVENTIONS

Applied Behavior Analysis (ABA): evidenced based therapy that encourages positive behaviors and discourages negative behaviors to improve a variety of skills

- Different types/styles of ABA:
  - Discrete Trial Training (DTT)
  - Early Intensive Behavioral Intervention (EIBI)
  - Early Start Denver Model (ESDM)
  - Pivotal Response Training (PRT)
  - Verbal Behavior Intervention (VBI)

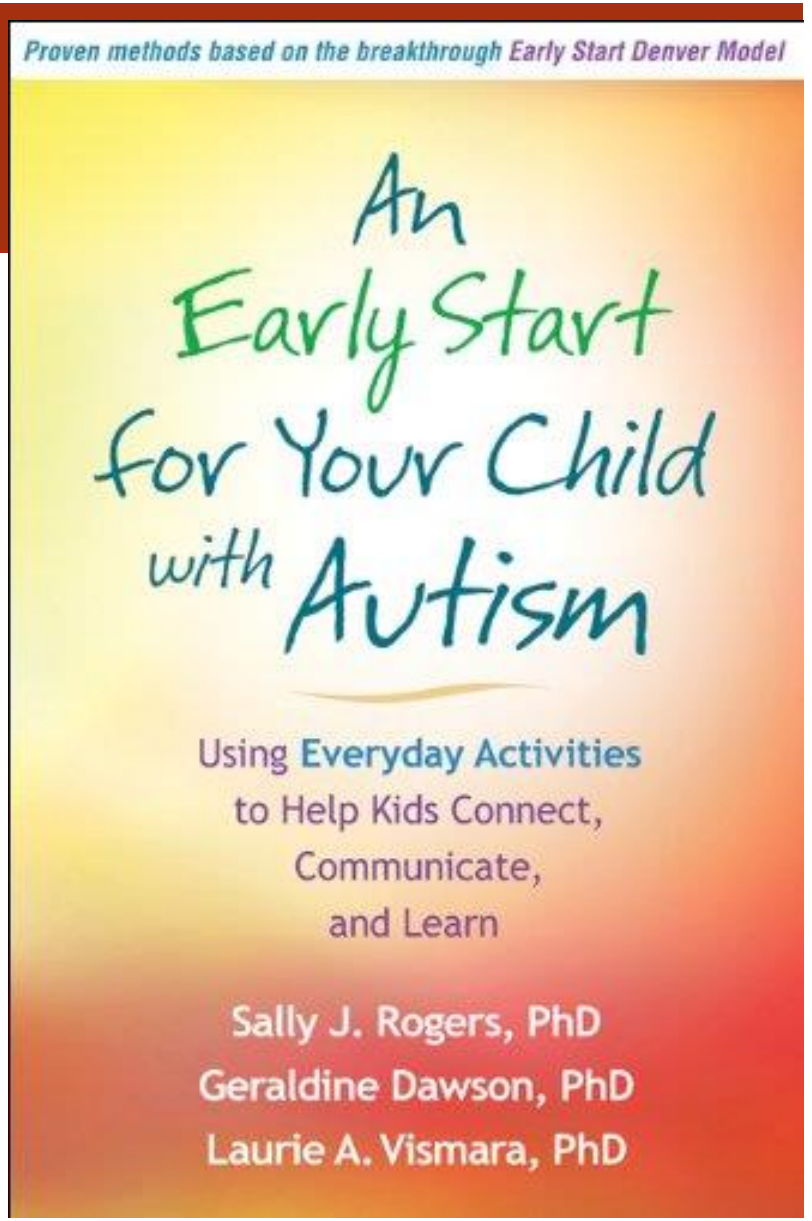
CONTROVERSY ABOUT ABA THERAPY

- Initial research by Dr. Lovaas in 1960s utilized positive reinforcement and punishment – at the time treating very "severely impaired persons" but utilized electric shock therapy
- Concern that use of discrete trial training repetitive and uncomfortable for children – less commonly used now, much more play based in most settings and more individual
- Concern that skills not generalizable – goes back to making sure skills being taught are relevant
- Concern that can be too focused on eliminating behaviors
- Early emphasis on eye contact (which is described by many autistic individuals as being truly uncomfortable) and decreasing stim behavior (can often serves a necessary self-regulation)

INTERVENTIONS

Early Start Denver Model (ESDM)

- Behavioral therapy based on ABA using play and daily routines
- Infants and toddlers
- Relationship-based intervention
- Provided in the child's natural environment
- Book written for parents: *An Early Start for your Child with Autism*



"What a good therapist does, whether it's ABA or not ABA, is to try and figure out ways that build on an individual child's strengths, that uses their interests, but that allow them to participate in society and that will give them the most choices. That is what we want. We don't want just the best-behaved person, we want a person who can do as much as possible, and get as much joy as possible out of the world."

- Dr. Catherine Lord

INTERVENTIONS

Speech-Language Therapy

- Increase functional and social communication
- Gestures & signs
- Augmentative & Alternative Communication (AAC
  - Picture exchange communication system (PECS)
  - AAC device

INTERVENTIONS

Occupational Therapy (OT)

- Encourage independence
- Self help / adaptive skills
- Sensory differences
- Emotional regulation
- Flexibility
- Play skills
- Attention

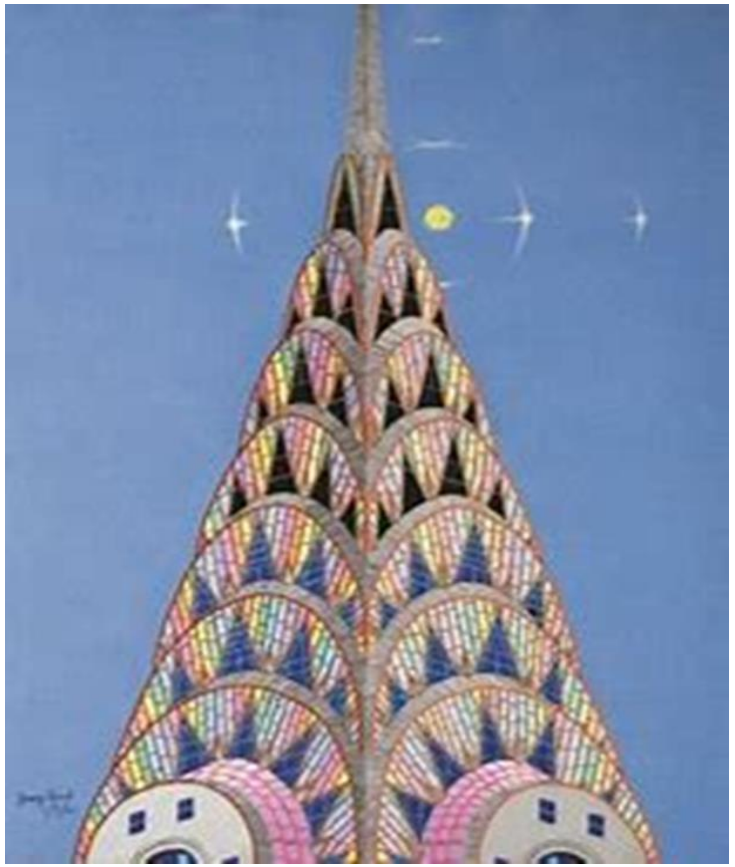
INTERVENTIONS

Physical Therapy

- Motor problems common in ASD
  - Coordination
  - Balance
  - Low tone
- Focus on strength, posture, & balance

COMORBID DIAGNOSES

- Discuss referral to genetics with family and encourage
- Screen for underlying medical issues
  - Sleep (50-80%)
  - Constipation (40-60%)
  - Seizures (10-20%)
  - Diet (often restricted, consider selected labs)
- Treat underlying medical issues- if new onset aggression or self injurious behavior keep in mind
- Screen for common psychiatric comorbidities
  - Anxiety (up to 80%)
  - ADHD (40-60%)
    - Inattentive presentation
    - Hyperactive Presentation
    - Combined presentation
  - Irritability (~30%)
    - With and without aggression



COMMUNITY CASE MANAGEMENT

- Case Management: Pts with autism may benefit from Targeted Community Case Management services for children with developmental disabilities and Specialized Section 28 services (ASD specific). In order to access community case management, parents need insurance that covers this service. Generally, most private insurances do not cover this service however MaineCare does, and families usually apply for MaineCare in their child's name. If it is determined that family is not eligible for MaineCare, they can then apply for the Katie Beckett program.
- List of organizations providing case management services can be found here: http://www.maine.gov/dhhs/ocfs/cbhs/provider-list/providers-reg1-mh-cm.html.
- Information about applying for MaineCare can be found at the Maine Department of Health and Human Services web site: http://www.maine.gov/dhhs/mainecare.html
- Information about the Katie Beckett program can be found here: https://www.maine.gov/dhhs/ocfs/cbhs/eligibility/katiebeckett.html
- Invite case managers to your visits- easier than tracking them down outside of clinic time and can be very helpful

WEBINARS AND ONLINE RESOURCES

- Autism speaks does have information available in many different languages – some outdated in terms of diagnosis – opportunity?
- Maine Pediatric and Behavioral Health Partnership https://bhpartnersforme.org/
  - sponsored Echo Autism Burst – recorded presentations will be online
  - Can also obtain psychiatric consultations – phone and video provider to provider
- Glickman Lauder Center of Excellence also had webinars available for viewing including one on medication https://www.mainehealth.org/maine-behavioral-healthcare/care-and-services/glickman-lauder-center-excellence-autism-and-developmental-disorders/webinars
- Of note, Glickman Lauder Center's waitlist for psychiatric services has shortened, must provide the original diagnostic evaluation with referral
- Autism Distance Education Parent Training (ADEPT) https://health.ucdavis.edu/mind-institute/centers/cedd/adept
- Free behavior modification app designed by Karen Bears PhD for parents of children with Autism: https://www.attendbehavior.com/maine
  - o For more info on the Attend Behavior App, contact Melinda Corey, Help Me Grow outreach specialist: Melinda.corey@maine.gov

LOCAL RESOURCES

Child Development Services (CDS)

https://www.maine.gov/doe/learning/cds

Maine Parent Federation

Family Support Navigator Program

http://mpf.org/

Autism Society of Maine

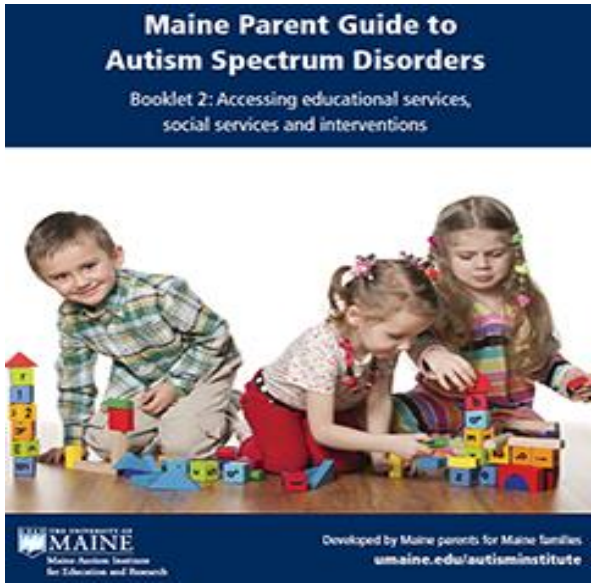
http://www.asmonline.org/

Autism Society's lending library (https://www.asmonline.org/library/)

Maine Autism Institute for Education & Research

https://umaine.edu/autisminstitute/resources/

https://umaine.edu/autisminstitute/wp-content/uploads/sites/150/2018/11/Parent-guide-4-2nd-ed.pdf



NATIONAL RESOURCES

- National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention ASD website: https://www.cdc.gov/ncbddd/autism/index.html
- CDC's Developmental Milestones: https://www.cdc.gov/ncbddd/actearly/milestones/index.html
- Tips to embed concepts in everyday routines available online at: https://www2.ed.gov/about/inits/list/watch-me-thrive/files/child-development-tips-for-ece-providers.pdf
- Autism Speaks: https://www.autismspeaks.org/
- Association for Science in Autism Treatment (ASAT) (https://asatonline.org/) provides up to date, scientific information about Autism Spectrum Disorder.
- An annotated ASD book list is available at https://www.autismspeaks.org/blog/books-about-autism.
- Positive parenting Resources: https://www.cdc.gov/parents/essentials/videos/index.html

RESOURCES FOR PROVIDERS

- Autism tookkit through AAP: Autism – Caring for Children With Autism Spectrum Disorder: A Practical Resource Toolkit for Clinicians (3rd Edition) https://publications.aap.org/toolkits/pages/Autism-Toolkit#clinical
- Article From the American Academy of Pediatrics| Clinical Report| January 01 2020 Identification, Evaluation, and Management of Children With Autism Spectrum Disorder https://publications.aap.org/pediatrics/article/145/1/e20193447/36917/Identification-Evaluation-and-Management-of?autologincheck=redirected

FOR 2 NEXT SESSION

- We have provided copy of ASD User's Manual including administration guidelines and scoring form
- Between now and next session expectation is that you review those materials as well as view at least suggested clip from the Vanderbilt site (included in instruction but will be viewing the 4/15/2020 session as most complete)
- We will be reviewing the administration next session with Dr. Popenoe and Dr. Youth
- For session with CDS- please email me your questions for CDS so that I can make sure that we address what YOU want to hear most

Scan the QR Code for the Vanderbilt Instruction Guide (Can also be found on the website in Session One)

https://www.maineaap.org/assets/resources/VKC-Learning-Instructions.pdf

QUESTIONS?