



UW PACC

Psychiatry and Addictions Case Conference

UW Medicine | Psychiatry and Behavioral Sciences

SOLVING THE PUZZLE:

ELIMINATING HEALTHCARE DISPARITIES IN THE DIAGNOSIS AND TREATMENT OF ASD

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HOPECENTRAL PEDIATRICS



SPEAKER DISCLOSURES

✓ I have no conflicts of interest to disclose.

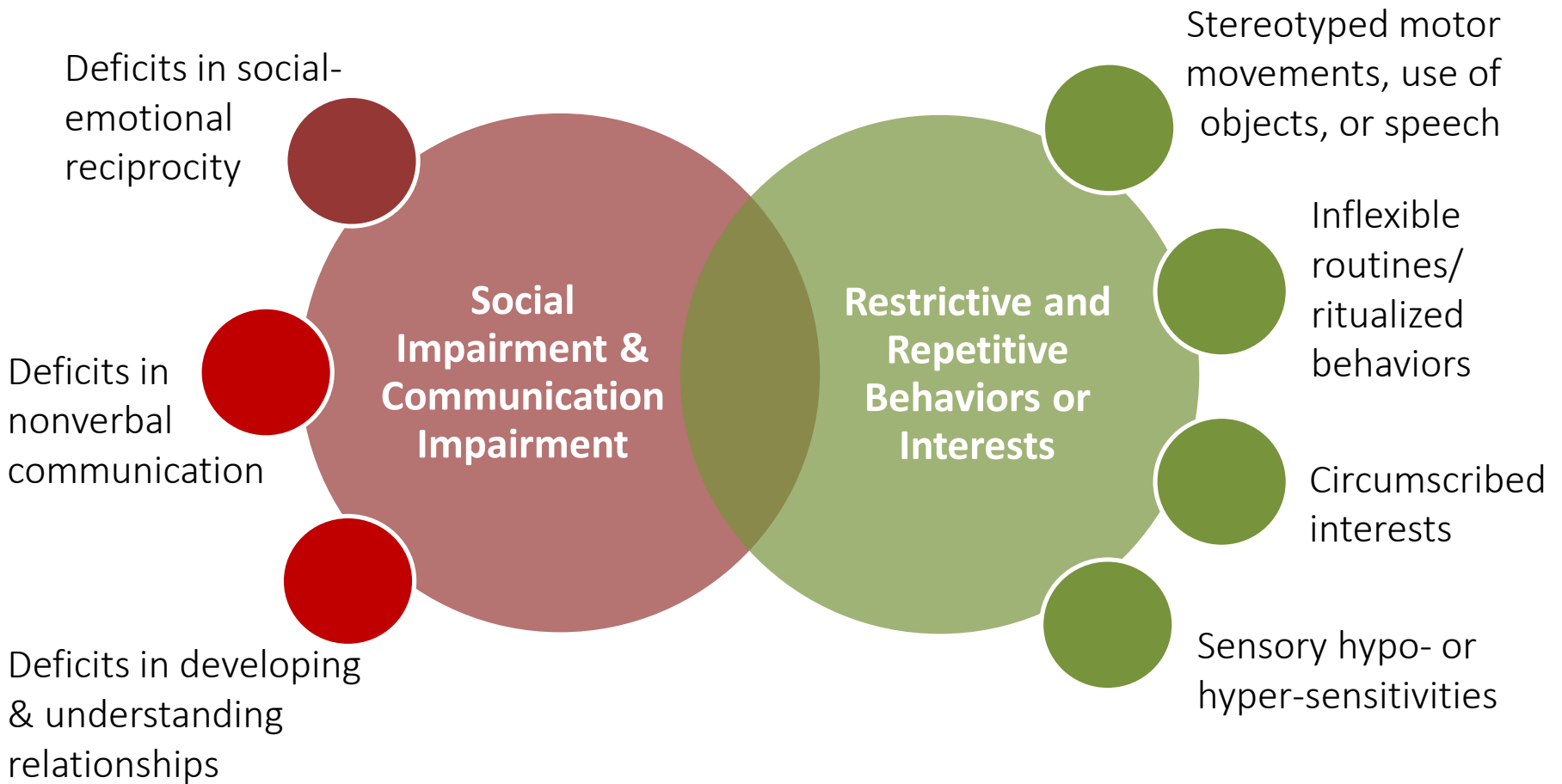
OBJECTIVES

1. Gain awareness of disparities in ASD diagnosis and treatment.
2. Learn strategies to address these disparities within the context of early childhood screening.
3. Gain practical steps to support patients and families following a positive ASD screen.

Overview

AUTISM SPECTRUM DISORDER

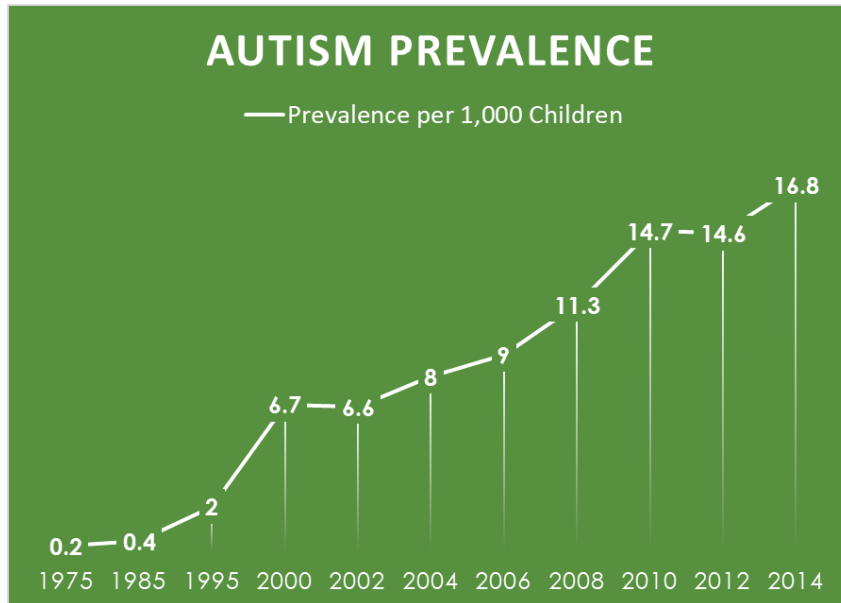
AUTISM SPECTRUM DISORDER



ASSOCIATED CONDITIONS

- Language impairments
- Motor deficits (e.g., odd gait, clumsiness, toe-walking)
- Sleep disorders
- Gastrointestinal problems (e.g., chronic constipation or diarrhea)
- Seizure disorders
- Restrictive eating
- Behavioral problems (e.g., self-harm, tantrums, elopement)
- Psychiatric conditions (e.g., anxiety, depression)
- Cognitive impairments (e.g., intellectual disability, executive function deficits)

AUTISM PREVALENCE

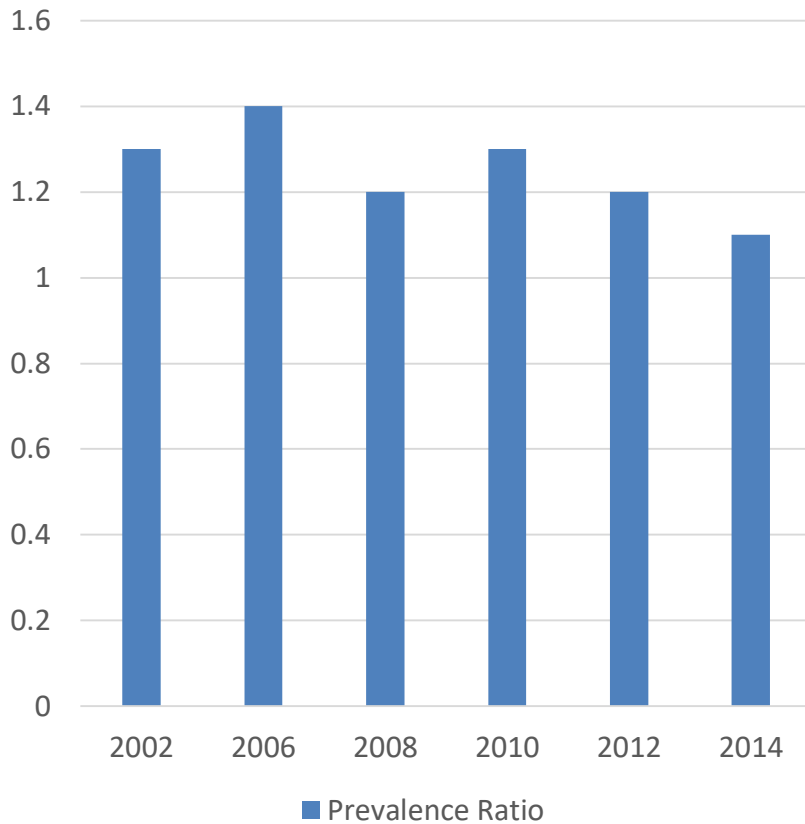


CDC's Autism and Development Disabilities Monitoring (ADDM) Network 2000-2014 combined data from all sites

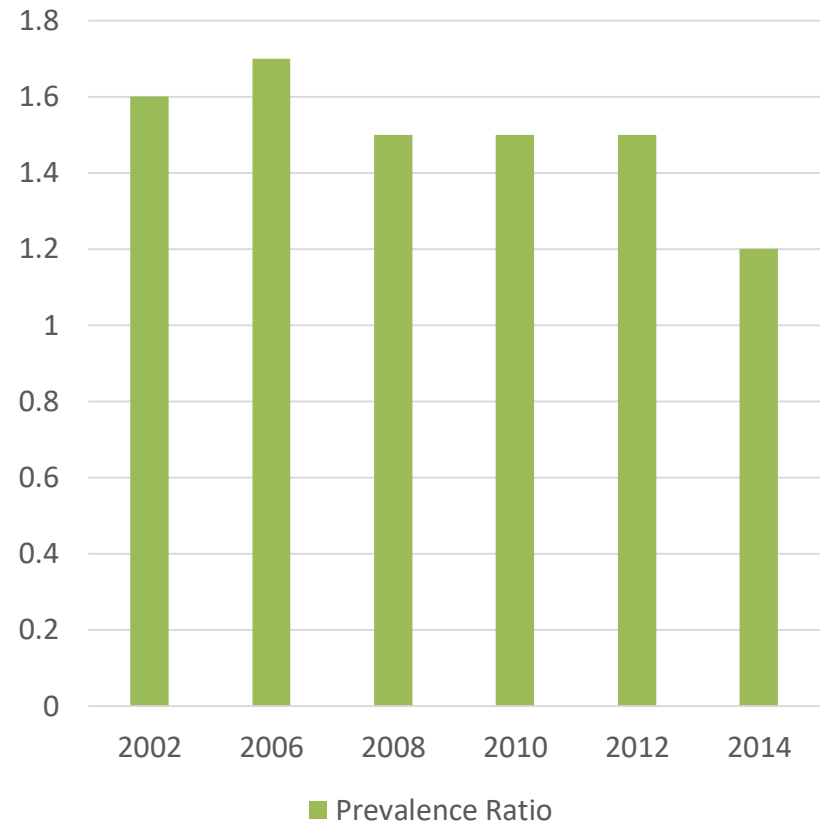
- Current prevalence rate = 1 in 54¹
- Prevalence by sex
 - Significantly higher rate of ASD among boys than girls (4:1)
- Prevalence by race/ethnicity
 - 7% higher in white than black children
 - 22% higher in white than Hispanic children
- Prevalence by SES
 - Higher identified ASD prevalence in neighborhoods with higher SES

RELATIVE INCREASES IN ASD

White to Black

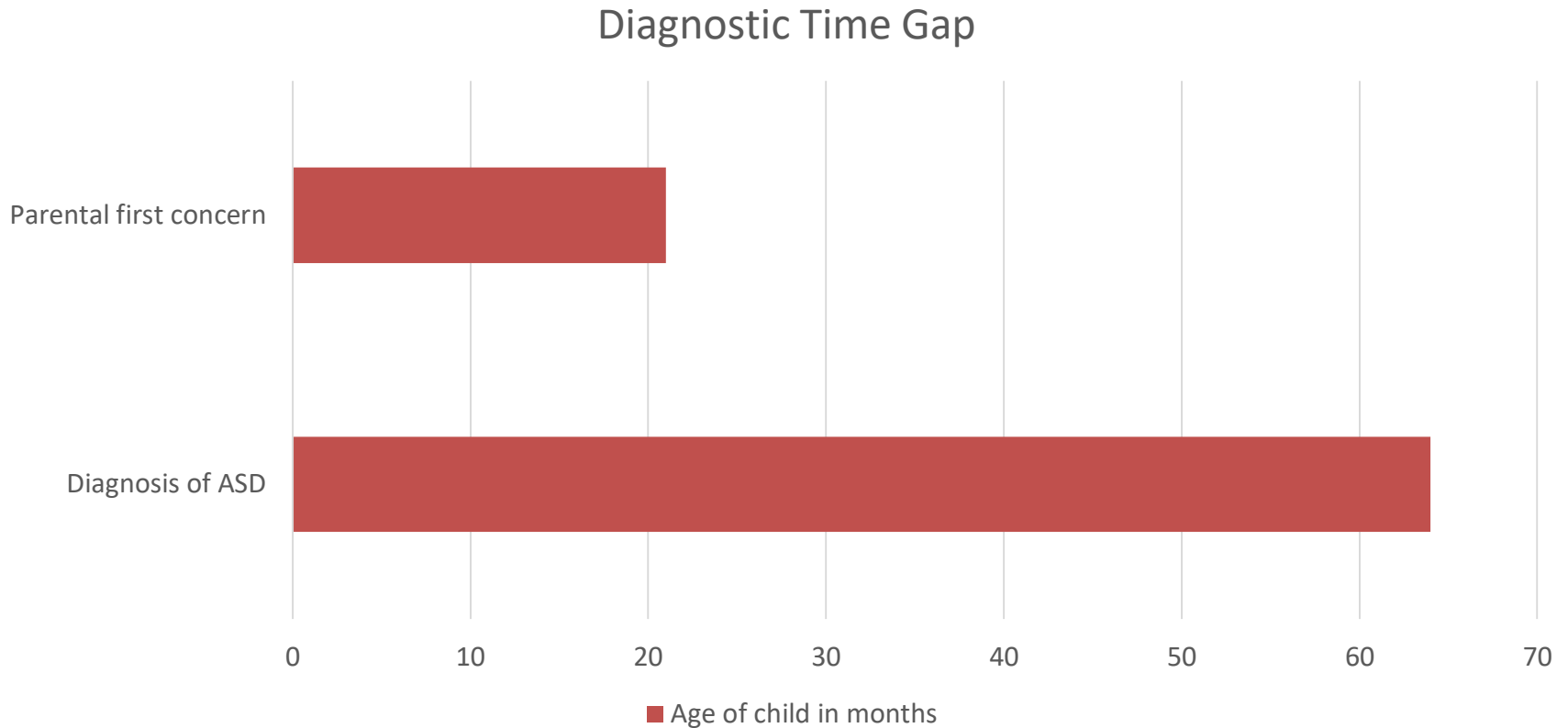


White to Hispanic



Community Report on ASD 2018

AGE AT DIAGNOSIS



Zablotsky et al. (2017); Zuckerman et al. (2020)

RACIAL/ETHNIC INCONGRUENCIES

- **Racial disparities in the age of diagnosis**
 - African American and multiracial children diagnosed later than white children
 - Hispanic ethnicity (English-speaking families) not found to be risk factor for age of diagnosis disparities
- Several studies found **no** difference in age of parents' first concern

Short & Schopler (1988); Ellingson et al. (2004); Mandell et al. (2002);
Mandell et al. (2009); Rosenberg et al. (2011); Twyman et al. (2009)

Autism Spectrum Disorder

EARLY CHILDHOOD SCREENING

ASD SCREENING GUIDELINES

- US Prevention Services Task Force
 - Insufficient evidence to recommend for or against universal screening because of limited data on:
 - Outcomes of children who screen negative
 - From diverse samples
- American Academy of Pediatrics
 - Autism-specific Screening at 18 and 24 months of age.
 - Does not endorse specific screening tool.

MODIFIED CHECKLIST FOR AUTISM IN TODDLERS (M-CHAT-R/F)

M-CHAT-R™

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

| | | |
|---|-----|----|
| 1. If you point at something across the room, does your child look at it? (FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?) | Yes | No |
| 2. Have you ever wondered if your child might be deaf? | Yes | No |
| 3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?) | Yes | No |
| 4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs) | Yes | No |
| 5. Does your child make <u>unusual</u> finger movements near his or her eyes? (FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?) | Yes | No |
| 6. Does your child point with one finger to ask for something or to get help? (FOR EXAMPLE, pointing to a snack or toy that is out of reach) | Yes | No |
| 7. Does your child point with one finger to show you something interesting? (FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road) | Yes | No |
| 8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?) | Yes | No |
| 9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck) | Yes | No |
| 10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?) | Yes | No |
| 11. When you smile at your child, does he or she smile back at you? | Yes | No |
| 12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?) | Yes | No |
| 13. Does your child walk? | Yes | No |
| 14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? | Yes | No |
| 15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do) | Yes | No |
| 16. If you turn your head to look at something, does your child look around to see what you are looking at? | Yes | No |
| 17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say “look” or “watch me?”) | Yes | No |
| 18. Does your child understand when you tell him or her to do something? (FOR EXAMPLE, if you don’t point, can your child understand “put the book on the chair” or “bring me the blanket?”) | Yes | No |
| 19. If something new happens, does your child look at your face to see how you feel about it? (FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) | Yes | No |
| 20. Does your child like movement activities? (FOR EXAMPLE, being swung or bounced on your knee) | Yes | No |

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- 2 stage screener
 - Stage 1: Questionnaire
 - 0-2 = low risk
 - 3-7 = moderate risk
 - 8-20 = high risk
 - Stage 2: Interview
 - Administer follow-up when M-CHAT-R score = moderate risk
 - If follow-up score > or = 2, refer for evaluation
- Sensitivity = 39%
- PPV = 15%

Guthrie et al. (2019)

RACIAL/ETHNIC INCONGRUENCIES

- Specificity and PPV higher in:
 - White children than black, Asian, or multi-racial children
 - English-only exposure compared to non-English exposure
- Cultural Translation
 - Some questions may not translate culturally.
 - May make inaccurate assumptions about caregiving systems.

SCREENING TOOL FOR AUTISM IN TODDLERS (STAT)



User's Manual
ages 24 - 36 months

- Psychometric properties:

- Ages 24-36 months
 - Sensitivity = .83
 - Specificity = .86
 - Concurrent validity with ADOS = .95
- Ages 14-24 months
 - Sensitivity = .93
 - Specificity = .73
 - PPV = .68
 - NPV = .97

SCREENING OF RACIAL/ETHNIC MINORITIES

- Psychometric properties for the STAT with racial/ethnic minorities or non-English speakers has not yet been studied.
- Holds the potential to minimize cross-cultural misinterpretations
- Eliminates reporter accuracy problems

TAKEAWAYS

- Universal screening:
 - Reduces age of diagnosis and, in turn, facilitates early intervention.
 - Holds potential to minimize influence of provider bias, if instruments are validated for racial/ethnic groups.
- It is important to understand the limits of screening tools.

Autism Spectrum Disorder

SHARED DECISION MAKING

SHARED DECISION MAKING (SDM)

- Decisions are collaboratively made by providers and patients, informed by evidence and weighted according to families' goals and values.
- Meta-analysis of over 100 RCTs found that SDM:
 - Improves patients' knowledge about treatment options
 - Provides patients with clarity about their health-related values
 - Increases patients' treatment adherence
 - Improves health outcomes

Legare et al. (2018)

SDM AND HEALTH CARE DISPARITIES

- PCPs less likely to do the following with BIPOC than White patients:
 - Use open-ended questions
 - Elicit details
 - Allow opportunities for patients to ask questions
 - Provide information on conditions

Matthew (2015)

PARENT COMMUNICATION ENGAGEMENT AT WELL-VISITS

LILJENQUIST ET AL., IN PROGRESS

- Objective
 - To assess parent conversation engagement patterns during WCC visit for children 2-24 months old
- Study Design
 - Audio recording of 87 WCC visits (n=44 English visits; n=43 Spanish visits) across 10 FQHCs were analyzed

DEVELOPMENT AND BEHAVIOR

| Parent Information Giving | English Speaking | Spanish Speaking |
|------------------------------|------------------|------------------|
| Cognitive Skills | 9 | 0 |
| Expressive Language | 41 | 12 |
| Fine Motor Skills | 18 | 1 |
| Gross Motor Skills | 42 | 14 |
| Receptive Language | 5 | 0 |
| Social/Emotional Development | 24 | 4 |
| Parent Question Asking | | |
| Cognitive Skills | 6 | 0 |
| Expressive Language | 4 | 0 |
| Fine Motor Skills | 1 | 0 |
| Gross Motor Skills | 5 | 5 |
| Receptive Language | 1 | 0 |
| Social/Emotional Development | 2 | 0 |

SDM TOOL

- **Choice Cards:**
 - Meant to be presented to families during the appointment for the purpose of guiding a discussion.
- **Caregiver Booklet:**
 - Meant to be sent home with families so they can review and rate treatment options based on their fit with family values and goals.



Autism Screening and Evaluation

A Decision Making Tool for Families
and Their Primary Care Providers



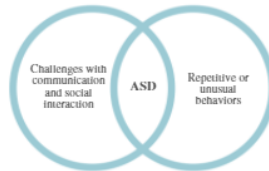
AUTISM OVERVIEW

Autism Overview

What is Autism Spectrum Disorder (ASD)?

Autism spectrum disorder (ASD) is a disability that impacts development. The two main components of ASD are:

1. Challenges with communication and social interaction
2. Repetitive or unusual behaviors



What does it mean if my child has a positive screen? screen for risk

A positive screen means that your child has some symptoms for ASD. Your provider should take a closer look to make sure everything is okay. A positive screen does not mean that your child has ASD.

How is ASD diagnosed?

A specialist will meet with a family and ask questions to learn about their child's behavior. The specialist will also observe the child through a series of activities or tasks.



The American Academy of Pediatrics recommends ASD screening at 18 and 24 months and general developmental screening at 9, 18, and 30 months.



Myths and Facts About ASD

What causes ASD?

Autism is largely a genetic condition. However, we have a lot to learn about other factors that may contribute to ASD.

Myth: Autism is caused by certain vaccines.

Fact: No studies have found any relationship between vaccinations and autism.

Myth: Autism is caused by cold or distant parents.

Fact: There is no relationship between parenting practices and ASD.

Can autism be cured?

Myth: Yes.

Fact: There is no known cure for ASD. However, there are several therapies that can be beneficial for children with autism. Evidence-based therapies for ASD include:

- Applied Behavioral Analysis (ABA) therapy
- Speech-language pathology
- Occupational therapy

ASD therapies are most beneficial when started early.

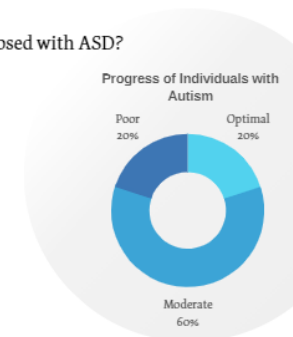
What does the future look like for a child diagnosed with ASD?

Myth: Children with autism can't learn or develop.

Fact: Of individuals diagnosed with ASD, about 20% will make optimal progress and 60% will make moderate progress.

We cannot predict which group a child will be in. This can be difficult for caregivers. We encourage caregivers to accept that their children will develop at their own pace.

Therapies can help children learn skills for everyday life.



NEXT STEPS

WATCHFUL WAITING



Description

Watchful waiting means you do not actively start the evaluation process or enrolling your child in therapies. You and your doctor keep an eye on how your child is developing.

Benefits ✓

- This is a no-cost option.
- You avoid unnecessary labeling of your child.
- You can start active treatment at any time.

Downsides ✗

- You lose time. Children with autism tend to have better outcomes if they start interventions earlier.
- It is possible that your child's symptoms will worsen.

AUTISM DIAGNOSTIC EVALUATION



Description

An evaluation will help you determine whether your child's symptoms are best explained by ASD. If ASD is diagnosed, the examiner will recommend specific therapies, supports and/or resources.

Benefits ✓

- A diagnosis provides clarity around your child's behavior and development.
- The more you understand your child's particular needs, the better you can help them.
- Certain services and resources are only accessible with an autism diagnosis.

Downsides ✗

- There are long wait times to get an autism diagnosis.
- Some insurance plans may not cover these evaluations.
- For some, there is concern about the stigma of an autism diagnosis. However, your info and diagnosis are kept between you and your provider.

DECISION MAKING

Compare Options

| | Reasons to Choose This Option | Reasons to Avoid This Option |
|-------------------------------------|---|--|
| Watchful Waiting | <ul style="list-style-type: none"> Lowest cost Avoid labeling your child | <ul style="list-style-type: none"> You lose time and symptoms may worsen |
| Autism Diagnostic Evaluation | <ul style="list-style-type: none"> Can access more services Can better understand child's condition | <ul style="list-style-type: none"> Long wait time Insurance may not cover diagnosis Concerns about potential stigma |
| Early Intervention Services | <ul style="list-style-type: none"> No diagnosis needed Offers support for navigating your child's development | <ul style="list-style-type: none"> May not be available in your preferred language Can be time consuming |
| Symptom Management | <ul style="list-style-type: none"> Can address immediate concerns Can work with your primary care provider | <ul style="list-style-type: none"> Does not address the root issue |
| Combined Approach | <ul style="list-style-type: none"> Maximize benefits and minimize risks | <ul style="list-style-type: none"> Can be overwhelming |

What are your family's short-term goals for your child?

What are your family's long term goals for your child?

What matters to you? (Rank each from 1-5)

| Cost | Time requirement | Getting clarity | Managing symptoms and behaviors | Gaining a support system |
|-------|------------------|-----------------|---------------------------------|--------------------------|
| _____ | _____ | _____ | _____ | _____ |

1. How well do you understand what your child's positive screen for ASD means?

I don't understand at all

 I somewhat understand

 I'm very confident in my knowledge

2. Which option(s) are you leaning towards? (Circle all that apply)

Watchful Waiting
 Autism Diagnostic Evaluation
 Early Intervention Services
 Symptom Management
 Combined Approach

3. Do you understand each option?

Yes No If no, please explain: _____

4. Do you understand the benefits and downsides of each option?

Yes No If no, please explain: _____

5. Do you have enough support and advice from others?

Yes No If no, please explain: _____

6. How sure are you about your decision?

Not Sure at All

 Somewhat Sure

 Extremely Sure

7. What would you need to feel more sure?

QUESTIONS?