You Screened for Autism Now What? A Case-Based Workshop for Pediatricians

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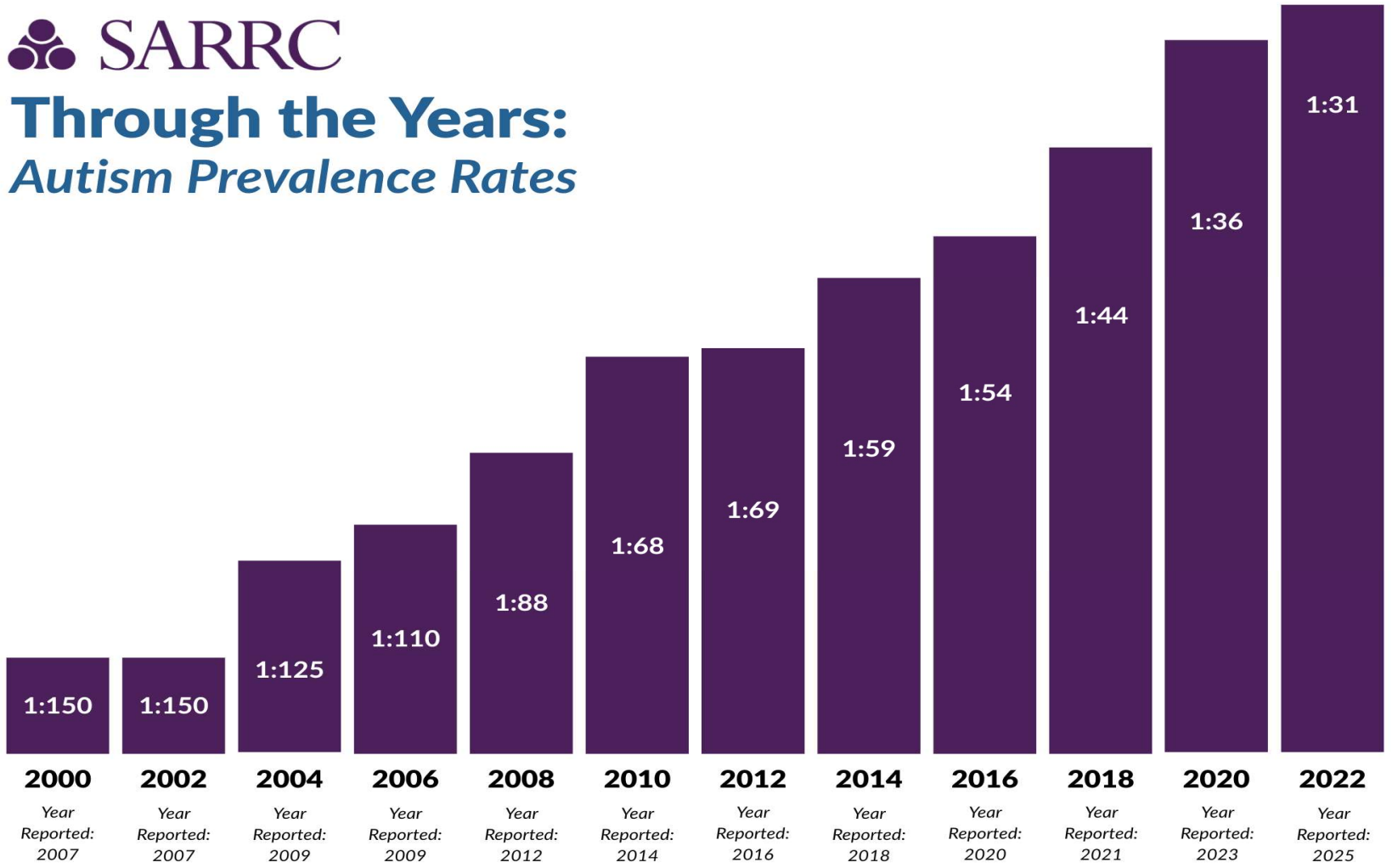
Disclosures

- Nothing to disclose

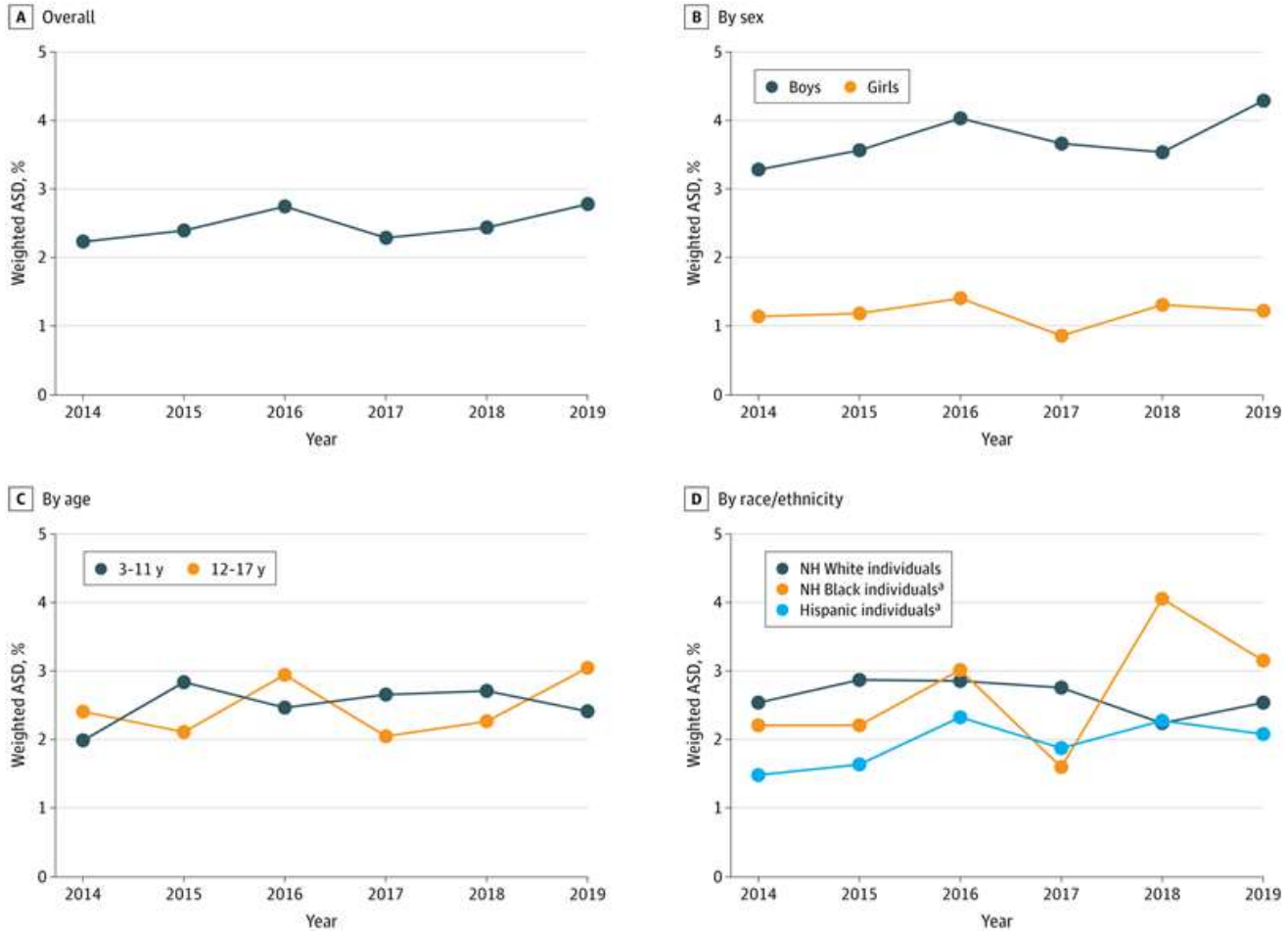
Objectives

- Differentiate between concerns that would require immediate specialty referral and developmental delays that can be managed in the medical home.
- Practice delivering a preliminary diagnosis of autism to families using empathetic, culturally sensitive, and jargon-free communication.
- Navigate the Arizona-specific referral landscape, ensuring referral locations are appropriate and correct documentation is provided.

Autism Prevalence



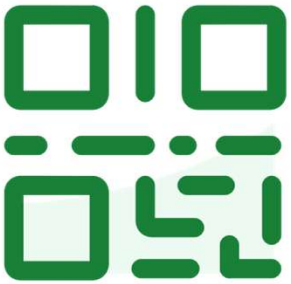
Demographics of autism



Yuan, Li, and Lu, 2021

Why this matters

- Pediatricians WILL take care of children with autism in their practice
- Median age of diagnosis 4-5 years
- Pediatricians are first line for identifying concerns
- Arizona has limited specialists for diagnosis
  - Long waitlists
- So much can happen before the diagnosis



Join at slido.com
#3312798

What do you feel most uncertain about when it comes to screening for autism

Join at slido.com #3312798

Autism in primary care

- Concerns are being identified earlier
  - Why?
    - Families are raising concerns earlier
    - Developmental surveillance is improving
    - Screening is now recommended universally

Hyman et.al., 2020

What parents notice

- Not speaking
- Limited response to name
- Decreased eye contact
- Easily upset
- Hand flapping

Surveillance

- Continuous longitudinal process
- Occurs at well child checks
- Full history – parental concerns, developmental history, milestones review
- NOT standardized

Lipkin et.al., 2020; Zubler, et.al., 2022

Screening

- Administering a validated standardized tool
- Universal developmental screening at 9, 18, and 30 month visits
- Autism specific screening at 18 and 24 month visits

Audience participation

Do you routinely administer the M-CHAT-R/F at 18 and 24 month visits

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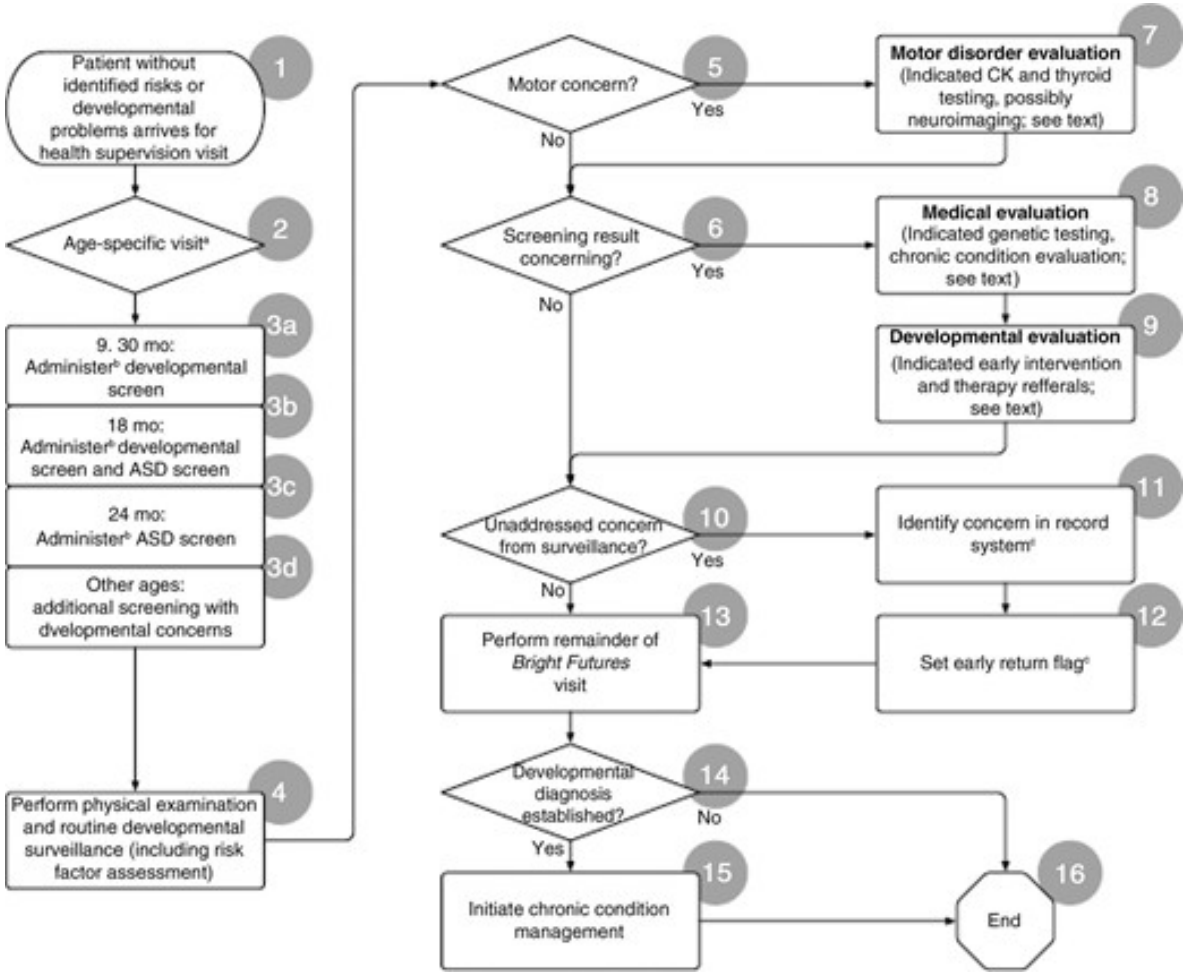
Screening



Lipkin et. al., 2020

Autism screening tools

Level 1

M-CHAT-R/F

Parent Report
+follow up q's

Age: 16-30 months

Validated and AAP recommended

Q-CHAT

Parent Report
(Likert scale)

Age: 18-24 months

Limited US validity, not widely adopted

Level 2

STAT

Clinician administered

Age: 24-36 months

Training required, longer administration

RITA

Clinician administered

Age: 18-36 months

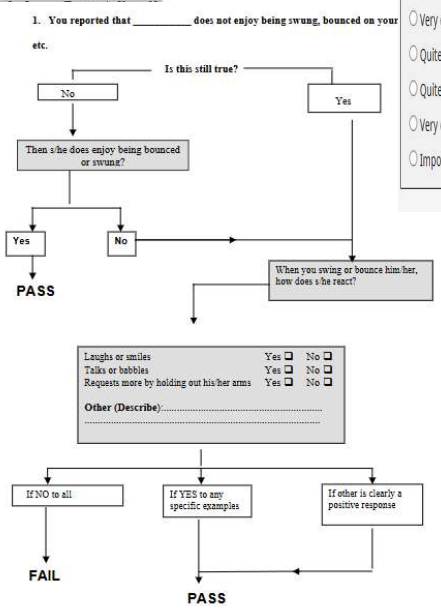
Brief, interactive, smaller validation samples

Trubanova Wieckowski, et.al., 2023, Choueiri et.al., 2015; Attar et.al., 2022; Allison et.al., 2008

M-CHAT

Please score the interview items on this page. Critical items are marked in **BOLD** and reverse score items, meaning those for which a score of "Yes" indicates risk for autism (11, 18, 20, 22) are noted by the word **REVERSE**.

1.	Does your child enjoy being swung, bounced on your knee, etc.?	Yes	No
2.	**Does your child take an interest in other children?**	**Yes**	**No**
3.	Does your child like climbing on things, such as up stairs?	Yes	No
4.	Does your child enjoy playing peek-a-boo/hide-and-seek?	Yes	No
5.	Does your child ever pretend, for example, to talk on the phone or take care of a doll or pretend other things?	Yes	No
6.	Does your child ever use his/her index finger to point, to ask for something?	Yes	No
7.	**Does your child ever use his/her index finger to point, to indicate interest in something?**	**Yes**	**No**
8.	Can your child play properly with small toys (e.g. cars or blocks) without just mouthing, fiddling, or dropping them?	Yes	No
9.	**Does your child ever bring objects over to you (parent) to show you something?**	**Yes**	**No**
10.	Does your child look you in the eye for more than a second or two?	Yes	No
11.	Does your child ever seem oversensitive to noise? (e.g., plugging ears) **(REVERSE)**	Yes	No
12.	Does your child smile in response to your face or your smile?	Yes	No
13.	**Does your child imitate you? (e.g., you make a face-will your child imitate it?)**	**Yes**	**No**
14.	**Does your child respond to his/her name when you call?**	**Yes**	**No**
15.	**If you point at a toy across the room, does your child look at it?**	**Yes**	**No**
16.	Does your child walk?	Yes	No
17.	Does your child look at things you are looking at?	Yes	No
18.	Does your child make unusual finger movements near his		
19.	Does your child try to attract your attention to his/her ow		
20.	Have you ever wondered if your child is deaf?		
21.	Does your child understand what people say?		
22.	Does your child sometimes stare at nothing or wander wit		
23.	Does your child look at your face to check your reaction v something unfamiliar?		



Q-CHAT

Instructions

Please answer the following questions about your child.

1. Does your child look at you when you call his/her name?

- ○ Always
- ○ Usually
- ○ Sometimes
- ○ Rarely
- ○ Never

2. How easy is it for you to get eye contact with your child?

- ○ Very easy
- ○ Quite easy
- ○ Quite difficult
- ○ Very difficult
- ○ Impossible

https://psychology-tools.com/test/qchat-quantitative-checklist-for-autism-in-toddlers

STAT
Screening Tool for Autism

https://vkc.vumc.org/vkc/triad/stat/

Robins, Fein, & Barton, 1999

What should Pediatricians use?

- Most common and currently recommended: M-CHAT-R/F
- Validated and recommended by AAP

Score	Action
0-2	Routine
3-7	Follow up
>/= 8	Refer/take action

Case Discussion

- 22 month old boy
  - Can say about 10 words
  - Lines up his cars
  - M-CHAT-R/F score of 5 – medium risk
  - Parents report “he is just strong willed and independent”

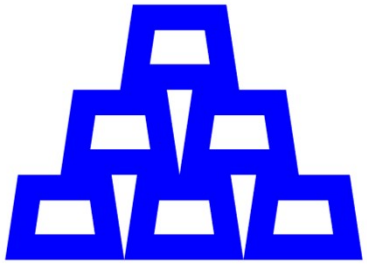
Let’s Discuss!

- What additional history do you want to know?
- What are you concerned about?

Autism criteria

Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history

Social-emotional reciprocity
Nonverbal communication
Relationships



Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history

Stereotyped or repetitive behaviors
Insistence on sameness
Focused interests
Sensory differences

Red flags


Autism Spectrum Disorder
Early Signs
ASD typically appears during the early years of life.
Early assessment and intervention are crucial to a child's long-term success.
no smiling at people by 6 months
no babbling, pointing, or meaningful gestures by 12 months
no two-word phrases by 24 months
no one-word communications by 16 months
poor eye contact
using or focusing in on parts of toys or objects
loss of skills at any time
not showing items or sharing interests
not responding to sounds, voices, or name
Talk to your pediatrician about concerns.
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National AutismCenter at MayInstitute
877.313.3833
nationalautismcenter.org

What about Speech and Language delay?

- Autism versus Language Delay
  - Children with autism CAN have language delay
  - Speech and language delay is NOT a criteria for autism
  - Nonverbal communication skills is a key part

	Autism	Language Delay
Pointing	Often absent	Present
Joint attention	Impaired	Intact
Social reciprocity	Reduced	Typical
Gestures	Limited	Typical
Eye contact	Reduced	Intact

Back to our case

- 22 month old boy
  - Can say about 10 words
  - Lines up his cars
  - M-CHAT-R/F score of 5 – medium risk
  - Parents report “he is just strong willed and independent”

What do you want to do next?

Watch and Wait?

There are concerns

- CHECK HEARING!
- CHECK HEARING
- CHECK HEARING
  - Note – children who are deaf and hard of hearing can have autism too
    - Diagnostic overshadowing

- Referral to intervention
  - <3 years of age – AzEIP
  - >3 years of age – developmental preschool
  - DDD
  - Private Therapies
    - Speech Therapy
    - Occupational Therapy

AZ State Services

- Birth to 3 years of age
  - Arizona Early Intervention Program (AzEIP)
  - Clinics can refer OR self referral
  - Criteria
    - At risk for developmental disability based on diagnosis
    - Delay in one or more developmental domain

https://azeip.azdes.gov/AzEIP/AzeipRef/Forms/Categories.aspx

AZ State Services

ARIZONA DEPARTMENT OF ECONOMIC SECURITY

Arizona Department of Economic Security

Your Partner for a Stronger Arizona

- Ages 3-6 years
  - DDD eligible with the following criteria
    - Autism Spectrum Disorder
    - Cerebral Palsy
    - Intellectual (Cognitive) Disability
    - Epilepsy
    - Down Syndrome
- Developmental preschool
  - Start enrollment at 2 year 9 months of age
  - Local school district
  - Do NOT need any official diagnosis
  - Does NOT need to be out of pull ups/diapers

AZ State Services

- 6 years of age and older
  - Autism
  - Cerebral Palsy
  - Epilepsy
  - Down Syndrome
  - Intellectual Disability
- With substantial functional limitations

Substantial Functional Limitations:

In addition to being diagnosed with at least one developmental disability, the person must show significant limitations in daily life skills due to their qualifying diagnosis in three **(3)** of the following. *(Note: The age of the person is taken in to consideration when identifying significant limitations in daily life skills.)*

Receptive and Expressive Language

- Cannot communicate with others
- Cannot communicate effectively without the assistance of others or a mechanical device

Learning

- Cannot participate in age appropriate learning without assistance

Self-Direction

- Needs assistance with making decisions that affect their well being
- Does not have safety awareness skills
- Needs help with personal finances

Self-Care

- Needs significant help with bathing, toileting, tooth brushing, dressing and grooming (taking care of themselves)
- The time to complete self-care activities takes so long it affects attendance or success in school, employment or other activities of daily living

Mobility

- Fine and gross motor skills are impaired
- Needs assistance from a mechanical device like a wheelchair or a walker to move from place to place
- The time it takes for the person to move takes so long that it affects keeping a job or completing activities of daily living

Capacity for Independent Living

- Needs daily supervision to help with health and safety
- This includes completing household chores, preparing simple meals, using microwaves or other household equipment, using public transportation and shopping for food and clothing

Economic Self-Sufficiency

- Can't perform tasks to keep a job
- Is limited in what they can earn
- Considering all expenses and the disability, the person earns below federal poverty level

For Questions Call Toll Free 1-844-770-9500 or E-mail DDDApply@azdes.gov

Early Intervention is Critical

- First few years of life – neural plasticity is the greatest
- Early intervention reduces intensity of support needed later in life
  - Even before any diagnosis is made
- Improved receptive/expressive language, social communication, daily living skills
- Intervention can be
  - Parent – led
  - Clinician focused

Back to the case

- Follow up at 24 month well check
  - Now can say 15 words, many scripted
  - Lines up his cars
  - Spins the wheels of any circular or wheeled item
  - Eye contact is inconsistent and he does not respond to joint attention
  - When going to the park he prefers to play with the wood chips and ignores children that approach him

  - In the clinic you notice the child
    - Does not regard the examiner
    - Flaps his hands when excited by holding and flapping the tape measure
    - Does not respond to his name when called
    - Lines up cotton balls on the counter and looks at them out of the corner of his eye

- MCHAT = 13
- Passed Audiology evaluation

Discussing autism concerns

- Autism Speaks Discussing the Diagnosis

Start Min 8:48 End 15:20 min

Should out to: Dr. Terry Katz and Dr. Beth Bennett

Talking about autism

- Parents often suspect something is different
- Receiving a (suspected) diagnosis can bring up a lot of emotions
  - Fear
  - Relief
  - Comfort
- The initial discussion will create a lasting memory for parents
- Allows them time to process as they await formal diagnosis

Presenting the Diagnosis

Components of the Session
1. Clinician describes the diagnosis in a clear, direct, and understandable manner.
2. Clinician discusses the diagnosis and supporting evidence in adequate detail.
3. Clinician provides reasons for hope and optimism.
4. Clinician explains the difference between a research outcome and an individual trajectory.
5. Clinician explicitly explains that family behavior is not the cause of their child's ASD diagnosis.
6. Clinician discusses diagnoses other than ASD, if appropriate.
7. Clinician asks the family for their reactions, questions and comments.
8. Clinician accurately summarizes the family's statements and questions.
9. Clinician answers family questions in an honest and direct manner.

Discussion of Next Steps

Components of the Session
1. Clinician makes key recommendations.
2. Clinician discusses and prioritizes next steps.
3. Follow-up meetings and/or phone calls are scheduled.
4. Clinician discusses ongoing support (if available).
5. Clinician provides written information.
6. Clinician gives information about the written report and what to expect.
7. The session ends on a positive note.

Let's Play Pretend

- Follow up at 24 month well check
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- MCHAT = 13

Let’s Play Pretend!

- Small groups (2 or 3)
- One person is the provider and the other is the parent(s)

Debrief

How did that go for everyone?

Common Pitfalls

- Waiting to see if the child “grows out of it”
- Not checking hearing early and consistently
- Assuming speech delay alone explains
- Reassuring without acting – “He’s just independent”
- Not referring to early intervention until after a formal diagnosis
- Overlooking subtle social communication deficits
- Focusing only on the M-CHAT score instead of the whole clinical picture
- Using jargon or overwhelming families during the initial conversation

Common myths/misconceptions about autism

- Myth: All autistic individuals have an intellectual disability
- Myth: All autistic people cannot speak
- Myth: Autism is caused by vaccines or medications taken during pregnancy
- Myth: Autistic people can’t show empathy & don’t want close relationships
- Myths: aggressive behaviors = autism ; autism = aggressive behaviors
- Myth: Behavioral challenges are always due to autism
- Children need an autism diagnosis to get therapies

A quick note - Current & Forward Thinking

- Embrace natural variations in functioning
  - Without dismissing the difficulties experienced by autistic individuals
  - Increasing focus on **patient-centered** outcome measures

- Recommendations must vary based on functional impact, co-occurring disorders, patient & family goals, etc.
  - Abilities & needs vary & will evolve over time

- Autistic individuals are entitled to receive equitable, dignified, & collaborative health care

- Promote inclusive & supportive environments for autistic people & provide necessary support to their families & caregivers

e.g., Hughes et al., (2023); Keating et al. (2022); Rosqvist et al., (2020); Silberman (2015); Singer et al. (2022)

Health Care for Youth With Neurodevelopmental Disabilities: A Consensus Statement

Carol Weitzman, MD,[a,]* Cy Nadler, PhD,[b,]* Nathan J. Blum, MD,[c] Marilyn Augustyn, MD,[d]
on behalf of the Supporting Access for Everyone Consensus Panel**

Pediatrics. 2024;153(5). doi:10.1542/peds.2023-063809

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Foundational Premises of SAFE Care

SAFE care is:

- Care that individuals understand and want;
- Individualized and evolving with the changing needs of a person;
- Accessible throughout the entire lifespan;
- Equitable and respectful;
- Defined and measured by patient experience, quality of care, and psychological well-being of patients and caregivers, and not solely by narrow interpretations of safety, efficiency, and remuneration.

SAFE care reduces or eliminates:

- Risk of physical and emotional harm to people, including accident, injury, restraint, and seclusion;
- Poor quality, inadequate, and incomplete care;
- Foregone care, which results in untreated healthcare conditions and increased morbidity.

EXECUTIVE SUMMARY
Healthcare for Youth with Neurodevelopmental Disabilities:
A Consensus Statement

SAFE Initiative
Supporting Access for Everyone

AUCD
Association of University Centers On Disabilities

DBPNet
Developmental Behavioral Pediatrics Research Network

Screenshot taken on 11/03/2024 from Executive Summary Health Care for Youth with Neurodevelopmental Disabilities: A Consensus Statement: https://safedbp.org/

Bill of Rights

American Academy of Pediatrics
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From: **Health Care for Youth With Neurodevelopmental Disabilities: A Consensus Statement**

Pediatrics. 2024;153(5). doi:10.1542/peds.2023-063809

NDD Healthcare Bill of Rights

Individuals with NDDs are human beings who are entitled to human rights and dignity. This **NDD Healthcare Bill of Rights** articulates that people with NDDs have the right to:

- Give or refuse consent/assent and participate in shared or supported decision-making.
- Access care that is proactively adapted to meet their needs.
- Use their preferred mode of communication (spoken words, sign language, AAC, etc.) and be communicated with in a format they can understand, with the support and technology they need.
- Receive effective pain and anxiety management.
- Advocate for their own needs and best interests.
- Receive care that is not traumatizing.
- Be treated as a person, not simply a diagnosis.
- Experience timely, courteous, and respectful care.
- Be free from restraint, coerced care, and maltreatment.

Figure Legend:

NDD Health Care Bill of Rights.

Conclusion

- Early Identification Matters
- Act on Concerns — Don’t “Watch and Wait”
- Communicate with Empathy
- Know the Arizona Referral Pathways
- Your Role Is Critical
  - **Pediatricians are often the first to notice concerns**
  - You can change a child’s developmental trajectory
  - Early, compassionate guidance supports families through uncertainty

Autism Educational Summit

Provider Day

Friday, September 25, 2026

Learn More:

https://AutismSummit.eventbrite.com

Phoenix Children's®

Thank you!

draz1@phoenixchildrens.com

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