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# NM ECHO Autism STAT: Assessment and Diagnosis of ASD in Pediatrics

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Autism Programs

Director, Capacity Building Initiatives

# Conflict of Interest Statement

- I have no financial disclosures to report

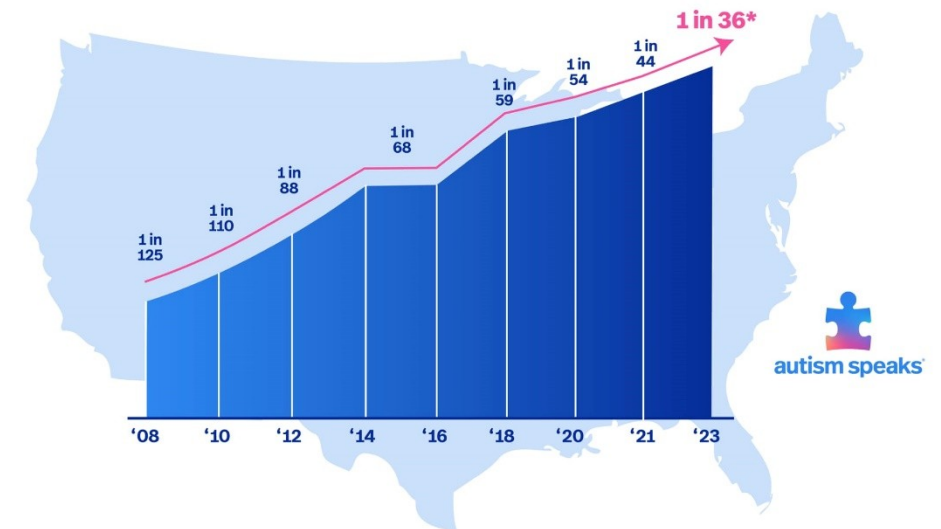
# Learning Objectives

- Review best practice ASD diagnostic assessment
- Understand ECHO Autism STAT Early Diagnostic Model for Primary Care
- Review research supporting ECHO Autism STAT model

# Autism Basics

- Complex neurodevelopmental condition
- Present from early in life (but no specific medical tests)
- Autism is common – Prevalence in 2023 was 1:36
- More boys diagnosed than girls\*
- Specific causes are not yet known, but there is a strong genetic component
  - *Younger siblings of autistic children have a 20% chance of also having autism*

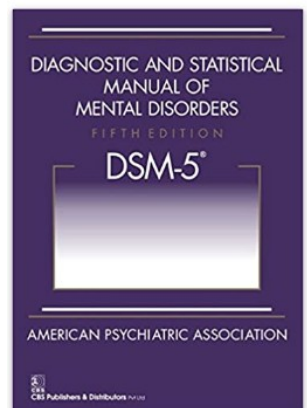
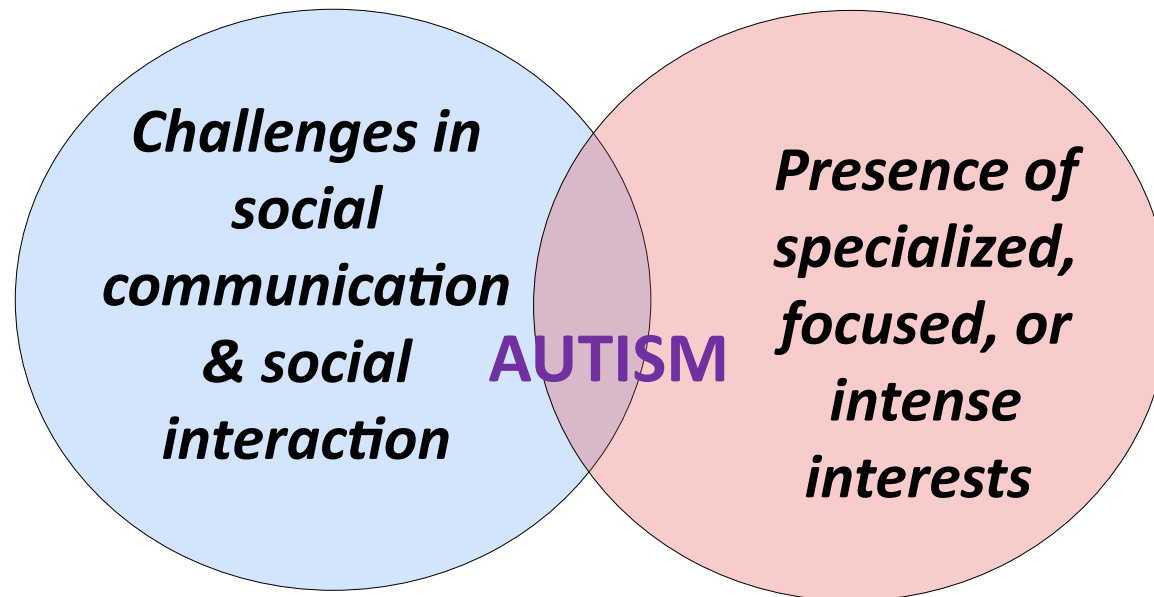
## Estimated Autism Prevalence 2023



The Centers for Disease Control and Prevention autism prevalence estimates are for 8-year-old children in the Autism and Developmental Disabilities Monitoring Network in 2020.

# Clinical Features of Autism

Formal diagnosis is based on behaviors  
in 2 broad domains:



The specific behaviors vary from child to child, across different contexts,  
and also change over time and across development

# Best Practice Evaluation

- ✓ Comprehensive history (developmental, past medical, social, family)
- ✓ DSM-5 criteria
- ✓ Structured behavioral observation
- ✓ Clinical expertise in autism and differential



Comprehensive History



Structured Behavioral Observation



CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

American Academy of Pediatrics



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Identification, Evaluation, and Management of Children With Autism Spectrum Disorder

Susan L. Hyman, MD, FAAP; Susan E. Levy, MD, MPH, FAAP; Scott M. Myers, MD, FAAP; COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS

# Early Support Services are KEY

## For Children

- Early, ***specialized*** services lead to significant gains in social, language, cognitive, and behavioral functioning
- Suggests that the features of autism that might affect quality of life are malleable

## For Caregivers

- Helps caregivers understand behaviors and learn strategies for interacting with and teaching their toddlers
- Can increase parenting self-efficacy and reduce parenting-related stress



# Current Challenges

- Long wait times
- Lack of specialists
- Rising rates of children needing assessment
- Misconceptions around autism
- Low comfort level of general pediatricians
- Lack of resources for intervention





# Innovation

- Utilize our specialists efficiently
- Build awareness
- Build foundational knowledge of learners
- Build community infrastructure
- Support neurodiversity

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# Moving Knowledge, Not People



**Extension for  
Community Healthcare  
Outcomes**



**Kristin Sohl, MD**  
Clinic Lead  
Pediatrician  
University of  
Missouri



# ECHO Autism: Primary Care

**OVERALL AIM:** Increase local access to high quality health care for children on the spectrum ASD

**TARGET AUDIENCE:** Primary Care Physicians/Practitioners

**FREQUENCY:** Twice, monthly 90-minute sessions

## HUB Team

- Pediatrician
- Clinical Psychologist
- Child and Adolescent Psychiatrist
- Dietitian
- Resource Expert
- Family Advocate

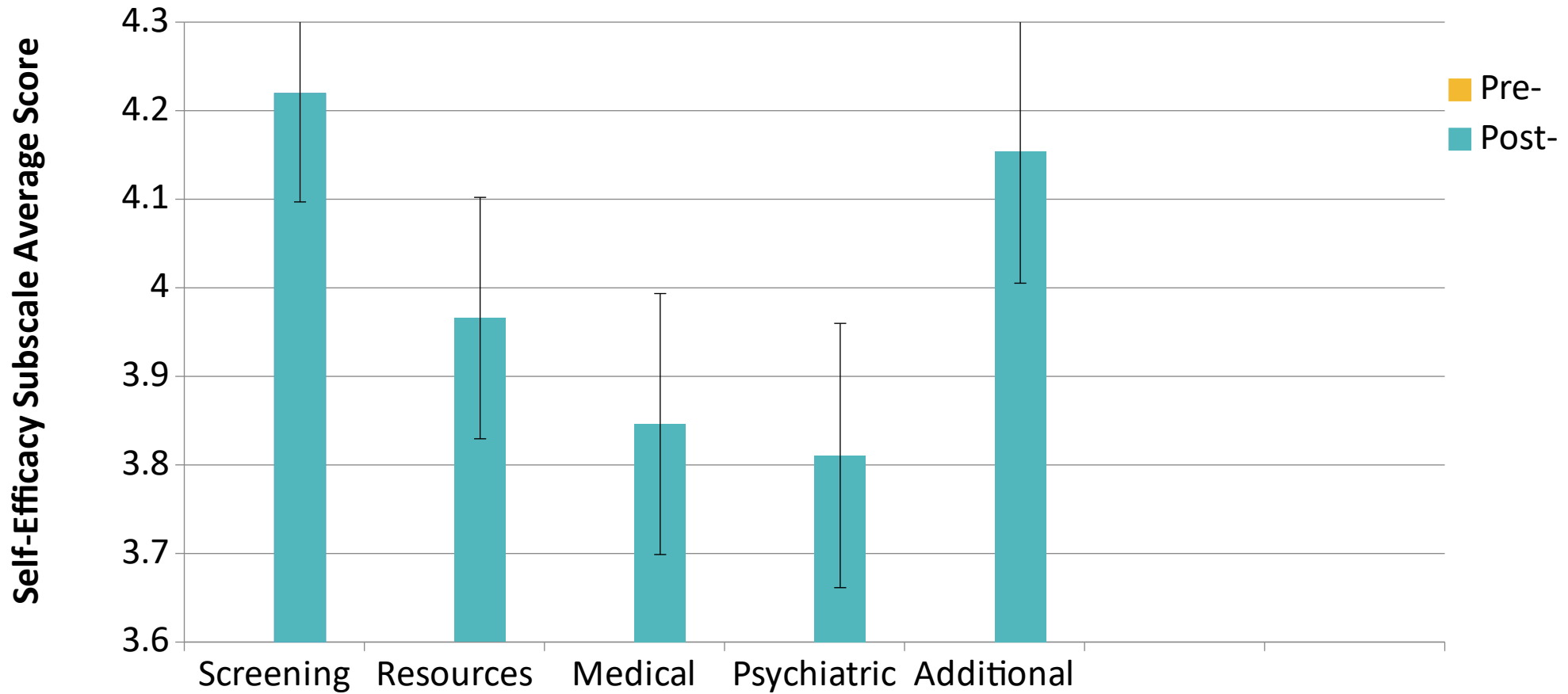
Sohl K, Mazurek MO, Brown R. ECHO Autism: Using Technology and Mentorship to Bridge Gaps, Increase Access to Care, and Bring Best Practice Autism Care to Primary Care. *Clin Pediatr (Phila)*. 2017;56(6):509-511. doi:10.1177/0009922817691825

# ECHO Autism Pilot Study

- Implementation of ECHO Autism was **feasible**
- PCP participants reported **high satisfaction** with the program
- PCPs demonstrated improvements in:
  - **Self-efficacy** in ASD screening and management
  - Use of ASD-specific **resources**

Mazurek, M. O., Brown, R., Curran, A., & Sohl, K. (2017). ECHO autism: A new model for training primary care providers in best-practice care for children with autism. *Clinical pediatrics*, 56(3), 247-256.

# Self-efficacy

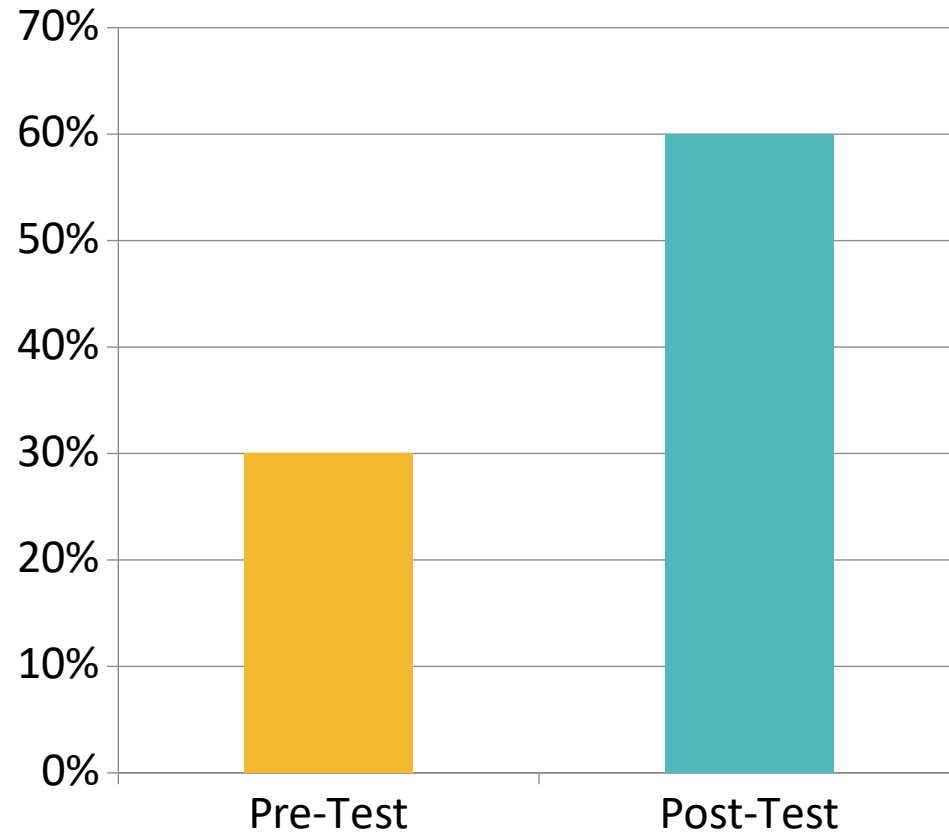


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  - Use of ASD-specific **resources**
  - Adherence to AAP **autism screening** guidelines

# AAP Screening Guidelines

Percentage of Pediatricians in Compliance with AAP Autism Screening Guidelines\*

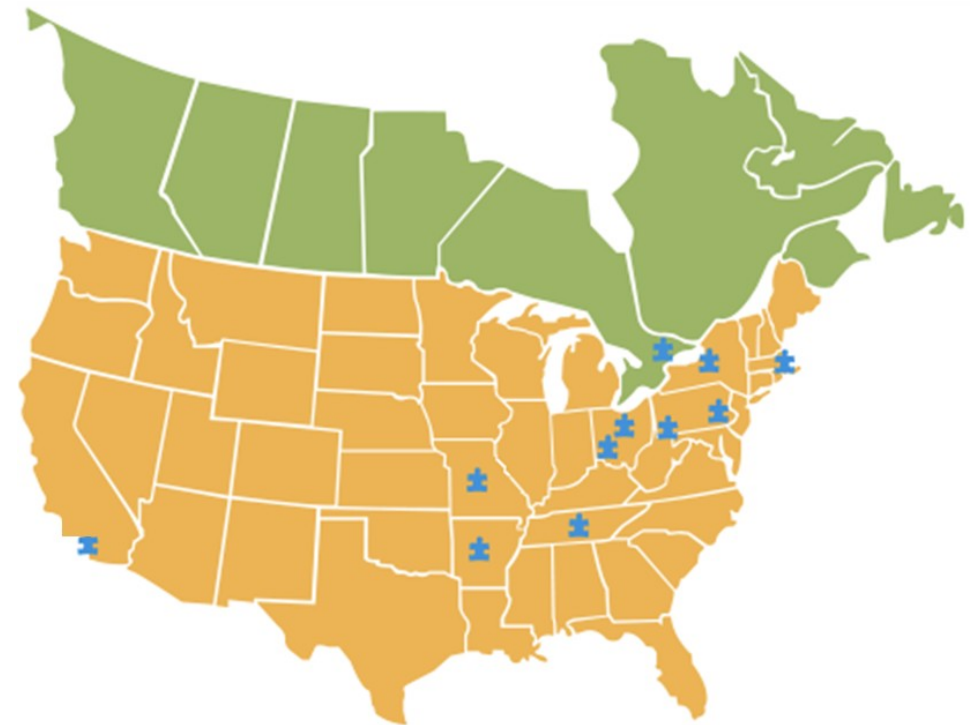
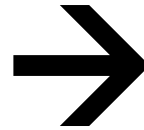


\*Using ASD-specific screening tools at 100% of 18-month and 24-month well-child visits conducted over the prior 6- month period.

# Pilot to 10 Site Replication Trial



Show-Me ECHO



ECHO Autism Replication Trial is funded by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under cooperative agreement UA3 MC11054 – Autism Intervention Research Network on Physical Health.



# Practice Change

↑ Increase in:

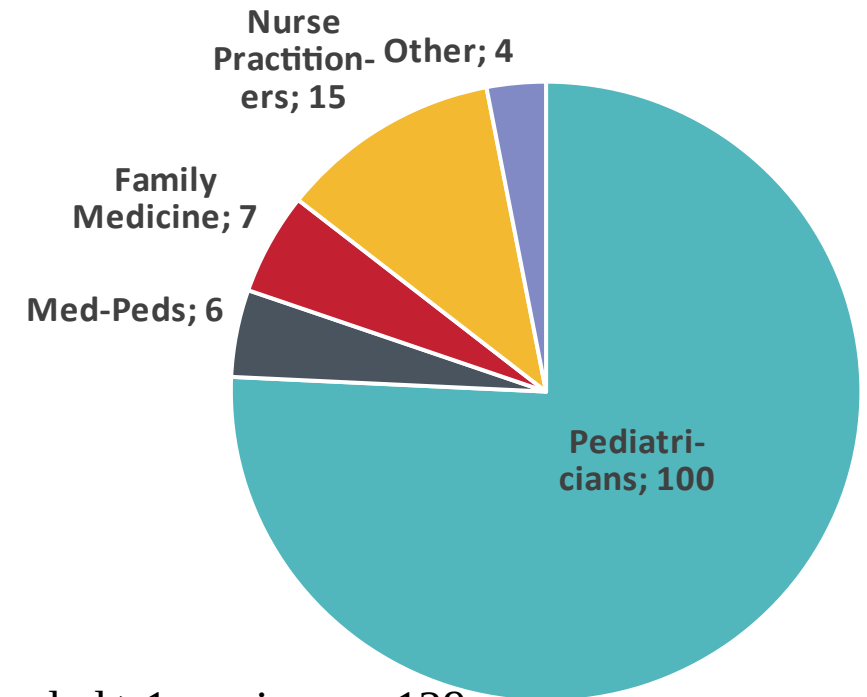
- **Autism screening**
- **General developmental screening**
- **Autism knowledge**
- Overall **self-efficacy**

↓ Decrease in:

- Number of **perceived barriers** to caring for children with autism in practice

Mazurek MO, Parker KA, Chan J, et al. Effectiveness of the Extension for Community Health Outcomes Model as Applied to Primary Care for Autism: A Partial Stepped-Wedge Randomized Clinical Trial. *JAMA Pediatrics*. 2020;174(5):e196306. doi:10.1001/jamapediatrics.2019.6306

Mazurek MO, Harkins C, Menezes M, et al. Primary Care Providers' Perceived Barriers and Needs for Support in Caring for Children with Autism. *The Journal of Pediatrics*. 2020;221:240-245.e1. doi:10.1016/j.jpeds.2020.01.014



Attended  $\geq 1$  session: n=129  
Average Attendance: 10 of 12 sessions



# ECHO Autism STAT Early Diagnostic Model

# Best Practice Autism Diagnostic Process



- Comprehensive history
  - DSM-5 categories
  - Past Medical + developmental/Social/Family
- Structured behavioral observation
  - i.e., STAT, ADOS, CARS

CLINICAL REPORT Guidance for the Clinician in Rendering Pediatric Care

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DEDICATED TO THE HEALTH OF ALL CHILDREN™

## Identification, Evaluation, and Management of Children With Autism Spectrum Disorder

Susan L. Hyman, MD, FAAP,<sup>a</sup> Susan E. Levy, MD, MPH, FAAP,<sup>b</sup> Scott M. Myers, MD, FAAP,<sup>c</sup> COUNCIL ON CHILDREN WITH DISABILITIES, SECTION ON DEVELOPMENTAL AND BEHAVIORAL PEDIATRICS



• Clinical expertise

# ECHO Autism Verified Diagnosis

ages 14-48 months



**Screening  
Results**



**Diagnostic  
Interview**



**Direct  
Behavioral  
Observation**

History and Physical  
Assessment



**Complete  
History and  
Physical**

**Clinical expertise through ECHO Autism**

# Screening Tool for Autism in Toddlers (STAT)



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*Stone et al., 2000; 2004; 2008*

- Consists of 12 play-based items
- Items assess key social-communicative behaviors
- Takes 20 minutes to administer
- Developed for children 24-36 months (*with provisional scoring down to 14 months and up to 48 months*)
- *Reliability process*



**Requesting**



**Directing attention**



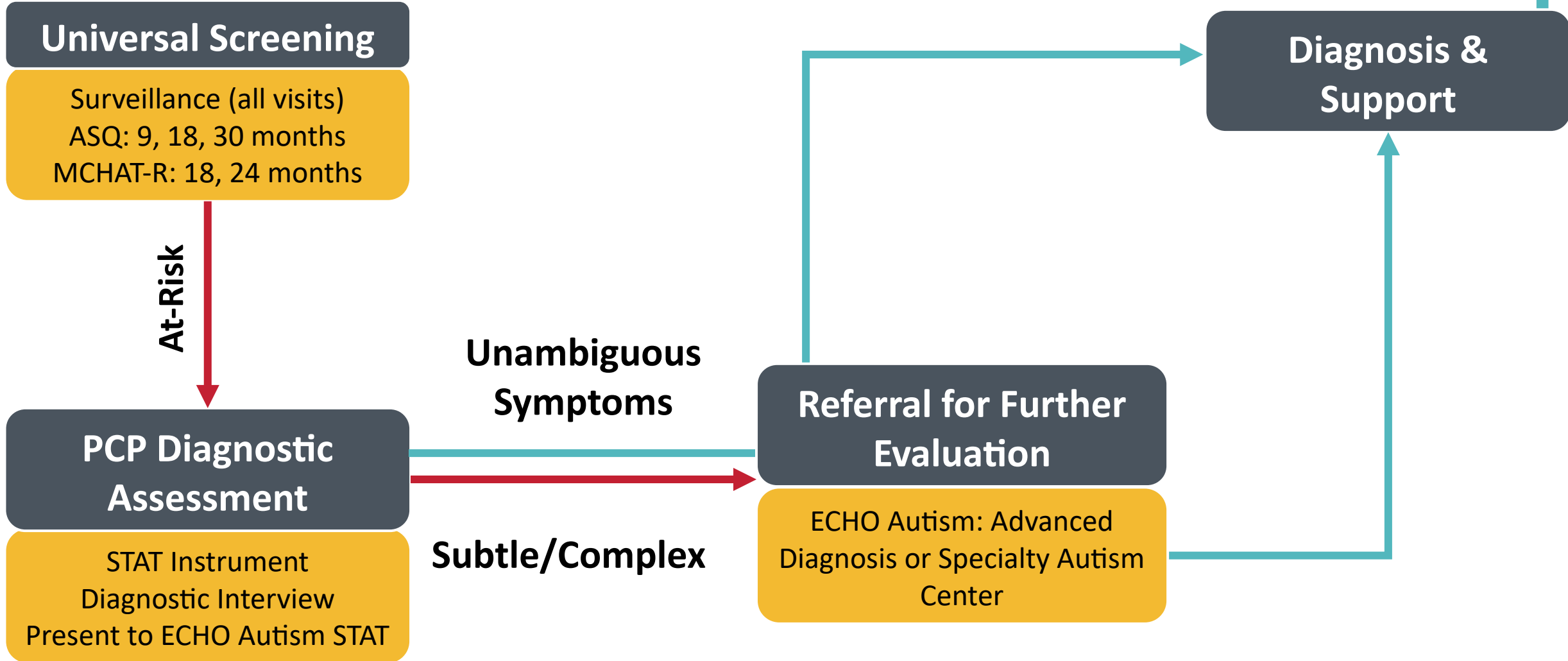
**Functional play  
& Turn-taking**



**Motor  
imitation**



# Multi-Tiered Autism Diagnostic Process



# Results Overview

- PCPs **↑ self-efficacy** in ASD screening, diagnosis and management
- Families avoid significant travel (~173 miles)
- Diagnostic wait time **eliminated/reduced** for families
- Expedited access to early intervention (~2-6 months)

Mazurek MO, Curran A, Burnette C, et al. ECHO Autism STAT: Accelerating Early Access to Autism Diagnosis. *J Autism Dev Disord.* 2019;49(1):127-137. doi:10.1007/s10803-018-3696-5

# ECHO Autism STAT: Diagnostic Accuracy Study



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Original Article

## ECHO (Extension for Community Healthcare Outcomes) Autism STAT: A Diagnostic Accuracy Study of Community-Based Primary Care Diagnosis of Autism Spectrum Disorder

Kristin Sohl, MD, FAAP,\*† Leeore Levinstein, MD,\* Alexandra James, MD, MPH, FAAP,\*†  
Sophia Greer, MPH,\* Katrina Boles, MS,† Alicia Brewer Curran, BS,† Melissa Mahurin, BA,†  
Micah O. Mazurek, PhD,‡ Valeria Nanclares, PsyD†

**ABSTRACT** *Objective:* Children can be reliably diagnosed with autism spectrum disorder (ASD) by a highly trained clinician as early as 12 to 24 months of age, but recent estimates indicate that the average age of diagnosis is 4.4 years. We hypothesized that trained primary care physicians and practitioners can reliably and accurately diagnose children 14 to 48 months with unambiguous symptoms of ASD. *Methods:* Through this diagnostic accuracy study, 20 patients diagnosed with ASD by clinicians trained through the ECHO (Extension for Community Healthcare Outcomes) Autism STAT program participated in an independent gold-standard evaluation at a regional autism center. Caregiver perceptions of the diagnostic process were also assessed. *Results:* Of the 20 patients who received a diagnosis of ASD by a trained clinician and completed the study, 19 diagnoses were confirmed by a gold-standard evaluation. Caregivers indicated that undergoing diagnosis in their local community rather than an autism specialty center was helpful (4.8/5 on a 5-point Likert scale, n = 19). Results of this study demonstrate that primary care clinicians can be trained to reliably diagnose ASD in children 14 to 48 months with unambiguous symptoms. *Conclusion:* Diagnosis in the primary care setting may lead to earlier diagnosis and quicker connection to evidence-based therapies and interventions. Given the potential impact of increasing access to high-quality diagnostic services, the role of primary care clinicians in the diagnosis of ASD should be further evaluated.

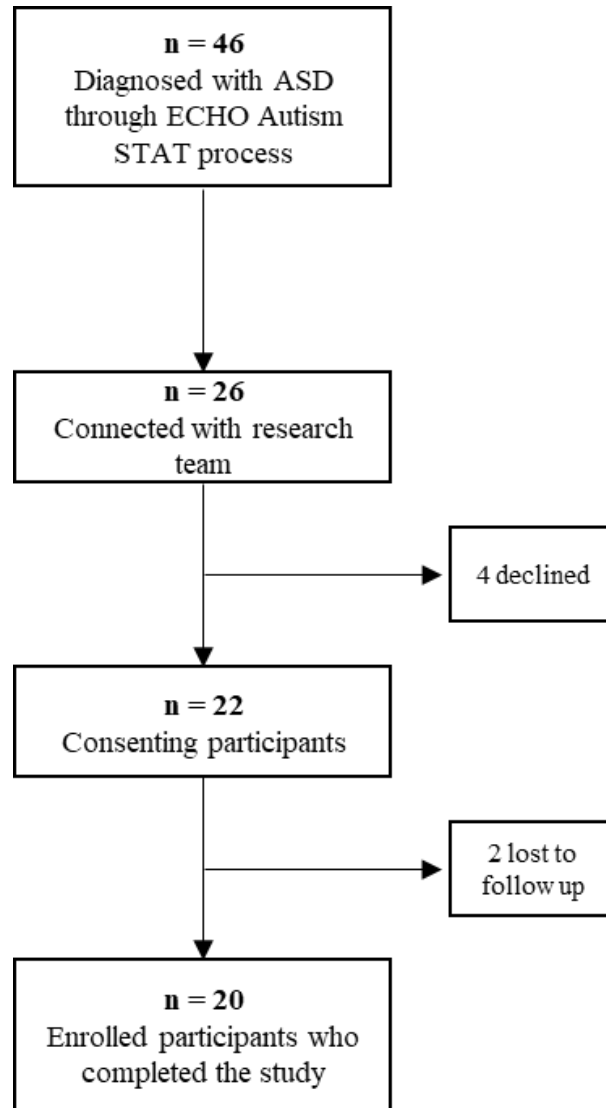
(*J Dev Behav Pediatr* 44:e177–e184, 2023) **Index terms:** autism, primary care, access, diagnosis.

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# Enrollment & Inclusion Criteria



- Children ages 14-48 months diagnosed with unambiguous characteristics of Autism by ECHO Autism STAT clinician (n=16) over a 9-month interval (Aug-June)
- English speaking
- Living in state

# Specialty Center Procedures

- Independent (of ECHO Autism) research reliable psychometricians or psychologists completed the diagnostic measures
- Measures included
  - Child Behavior Checklist (CBCL)
  - Adaptive Behavior Assessment System (ABAS)
  - Differential Ability Scale – 2 (DAS-2) or Mullen Scales of Early Learning
  - Autism Diagnostic Observation Schedule (ADOS-2)
  - DSM-5 diagnostic checklist
  - Comprehensive history

# Results

- 95%\* diagnosed with ASD by comprehensive autism assessment in concordance with ECHO Autism STAT PCP diagnosis

ECHO AUTISM STAT PCP RESULTS				
	Mean Score (SD)	At Risk	N	
M-CHAT Total Score	7.7 (4.7)	89%	19	
STAT Sum of Domain Scores	3.2 (0.8)	95%	20	
DIAGNOSTIC CENTER EVALUATION RESULTS				
	Mean Score (SD)	N		
DAS-II GCA	72 (7.56)	6		
DAS-II Nonverbal	84.5 (14.24)	6		
DAS-II Verbal	75 (14.35)	6		
Mullen Early Learning Composite Standard Score	52.15 (7.68)	13		
Mullen Visual Reception Percentile Rank	7.75 (15.77)	8		
Mullen Visual Reception T Score	24.64 (8.56)	14		
	Mean (SD)	N	Percent classified	Modules
ADOS Calibrated Severity Score	8.3 (1.78)	20	95%	Module 1, n=14 Module 2, n=1 Module 3, n=1 Toddler, n=4

Table 1 (partial): Results of standardized assessment measures for ECHO Autism STAT PCP evaluation and independent specialty diagnostic center assessment.

# Caregiver Measure Results

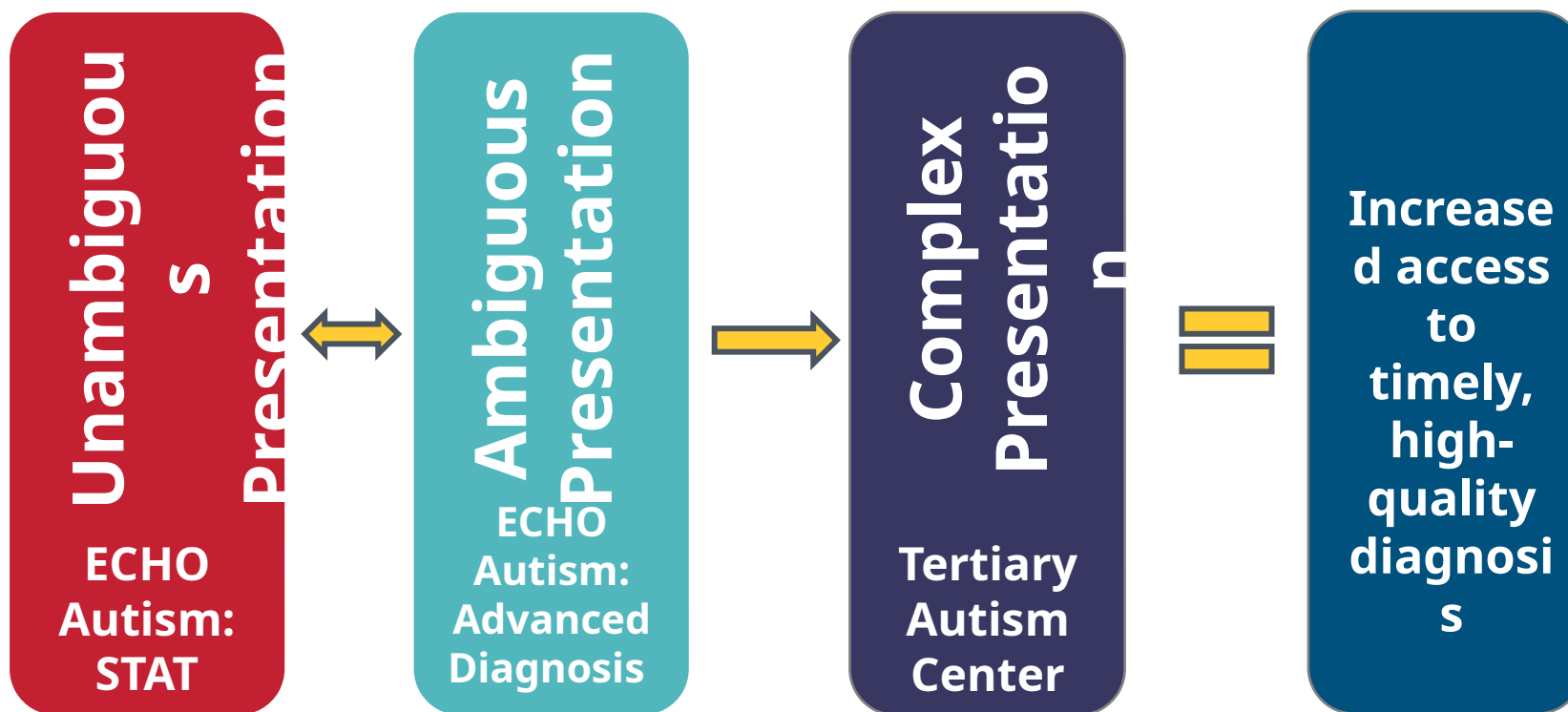
- 73% preferred receiving care for their child's ASD diagnosis with a community clinician rather than an autism specialty center.
- Top barriers families reported to accessing specialty centers
  - cost of travel (60%, n=12),
  - needing to miss work (50%, n=10),
  - waitlist/not getting an appointment quickly (45%, n=9)
  - cost of services (35%, n=7),
  - lack of reliable transportation (25%, n=5)
- On the MPOC-20, caregivers reported strong indicators of family-centeredness
  - perceptions of PCP providing enough time to discuss diagnosis (mean 6.55/7, SD 0.89, n=20),
  - providing a caring atmosphere rather than just providing information (mean 6.65/7, SD 0.75, n=20)

	N	Mean (SD)
I feel confident in the diagnosis my child received from our ECHO Autism Provider	19	4.74 (0.45)
I am satisfied with the evaluation my child received from our ECHO Autism Provider	19	4.68 (0.48)
I feel comfortable disagreeing with our ECHO Autism Provider	19	4.47 (0.96)
Our ECHO Autism Provider listens to me when I express concerns	19	4.84 (0.37)
Our ECHO Autism Provider takes my concerns seriously	19	4.84 (0.37)
Our ECHO Autism Provider has experience working with children who have autism	19	4.47 (0.77)
Our ECHO Autism Provider is knowledgeable about autism	19	4.68 (0.58)
Our ECHO Autism Provider is sensitive to my child's needs	19	4.73 (0.56)
Our ECHO Autism Provider is sensitive to my needs as my child's caregiver	19	4.68 (0.58)
Our ECHO Autism Provider explained my child's diagnosis in a way I could understand	19	4.68 (0.58)
Our ECHO Autism Provider helped me find resources for my child	19	4.74 (0.56)
Our ECHO Autism Provider answered my questions about my child's development	19	4.74 (0.45)
It was helpful for my child to be evaluated in our own community rather than traveling to an autism center	19	4.79 (0.54)

Table 2: Select items from the ECHO Autism STAT Parent Survey. Scores based on a 5-point Likert scale with 1=Strongly disagree; 5 = Strongly agree

# ECHO Autism Communities Diagnostic Model

Right Care, Right Time, Right Place



# NM ECHO Autism Projects Underway



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## Primary Care STAT Early Diagnostic Model

- STAT training March 12-13, 2024 for 16 primary care providers (pediatrician, PA, NP). Next cohort starting March 6-7, 2025



Courtney Burnette, PhD  
Clinical Psychologist



Gabriel Anzueto, MD  
Developmental Behavioral  
Pediatrician, UT Houston

- STAT reliability process underway
- ECHO sessions on the 2<sup>nd</sup> and 4<sup>th</sup> Tuesdays of the month from 12:30-2pm
  - Management of symptoms
  - Diagnostic consideration (ages 14-48 months)



Lauriann King, CFPSW  
Certified Family Peer



Elisheva Levin, PhD  
Autist  
Parent of an autistic adult

Unambiguous  
Presentations

ECHO  
Autism:  
STAT



# NM ECHO Autism Projects Underway



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Ambiguous  
Presentation

ECHO  
Autism:  
Advanced  
Diagnosis

## Advanced Diagnosis

- ADOS-2 (Autism Diagnostic Observation Schedule, Second Edition) Training February and August 2024 for 26 providers mostly psychologists
- ECHO sessions on the 2<sup>nd</sup> and 4<sup>th</sup> Thursdays of the month from 12:30-2pm



Courtney Burnette, PhD  
Clinical Psychologist



Mohammad Murtuza, MD  
UNM Child and Adolescent  
Psychiatry Fellow



Lauriann King, CFPSW  
Certified Family Peer



Elisheva Levin, PhD  
Autist  
Parent of an autistic adult



# Opportunity

## Current Model

- Diagnostic bottlenecks
- Inequitable access
- Extensive resource utilization
- Family stress
- Limited community clinician knowledge and self-efficacy
- Diagnostic islands

## New Directions

- Tiered approach to optimize access
- Distributed access
- Family choice
- Community professional engagement and self-efficacy
- Longitudinal, health home for children on the autism spectrum



# ECHO Autism Communities Screening/Assessment/Diagnosis

- Hands on training + ECHO Autism
  - ADOS
  - STAT
- Develop local expertise and community access
- Partnerships between ECHO Autism: STAT and Diagnostic providers
- 600+ diagnostic assessments

