Autism Spectrum Disorder Management in Primary Care

Annie Inge, Ph.D., Children's National Center for Autism Spectrum Disorders
Michael Mintz, Psy.D., Children's National Child Development Clinic
Cathy Scheiner, M.D., Children's National Neurodevelopmental Pediatrics Clinic

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A few notes about today's Grand Rounds

- All lines are muted throughout the presentation.
- Please use the Q&A to ask questions or make comments.
- We will be recording the session.
- Today's recording and materials will be posted to the PHN website 3 business days following the presentation:

https://pediatrichealthnetwork.org/

Speakers

Annie Inge, Ph.D.
Clinical Psychologist
Clinic Director, Center for
Autism Spectrum Disorders

Michael Mintz, Psy.D.
Clinical Psychologist
Associate Director,
Child Development Clinic

Cathy Scheiner, M.D.
Developmental-Behavioral
Pediatrician,
Neurodevelopmental
Pediatrics & Neurogenetics

Disclosures: None

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Objectives for Today's talk

1. Identify autism in the primary care setting
2. Differentiate those children who may need level II and level III diagnostic evaluations
3. Implement preliminary, evidenced based interventions for children with suspected or diagnosed ASD

Epidemiology

Racial and SES disparities in access to early identification/diagnosis

- Overall median age of first dx - 51mos (2016)
- Black & Hispanic children less likely to have 1st time evaluation before 36mos when compared to white children

Gender Ratio:

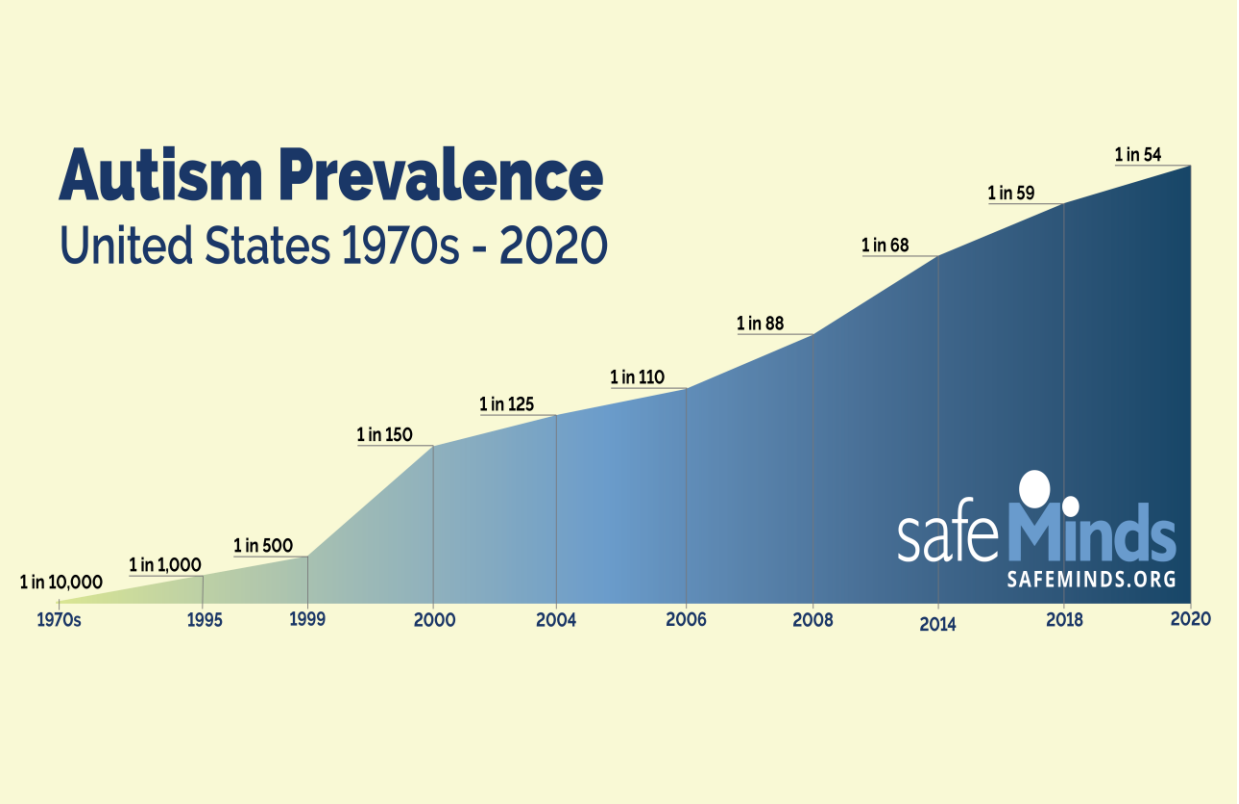
- >4 times more common boys vs girls

Cognitive Functioning

- 33% with IQ<70

Barriers to Services Exist

- Waitlists for diagnostic and treatment services
- Network inadequacies
- Requirements to document ASD



CDC, Autism and Developmental Disabilities Monitoring Network, Period Covered: 2016

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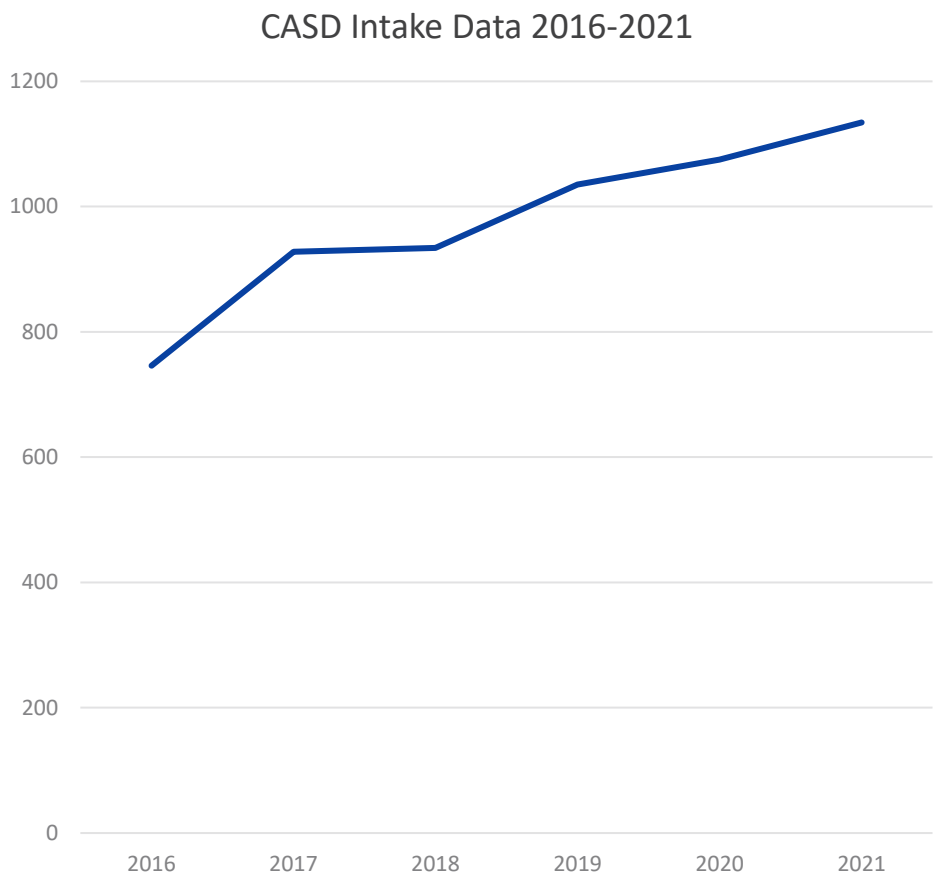
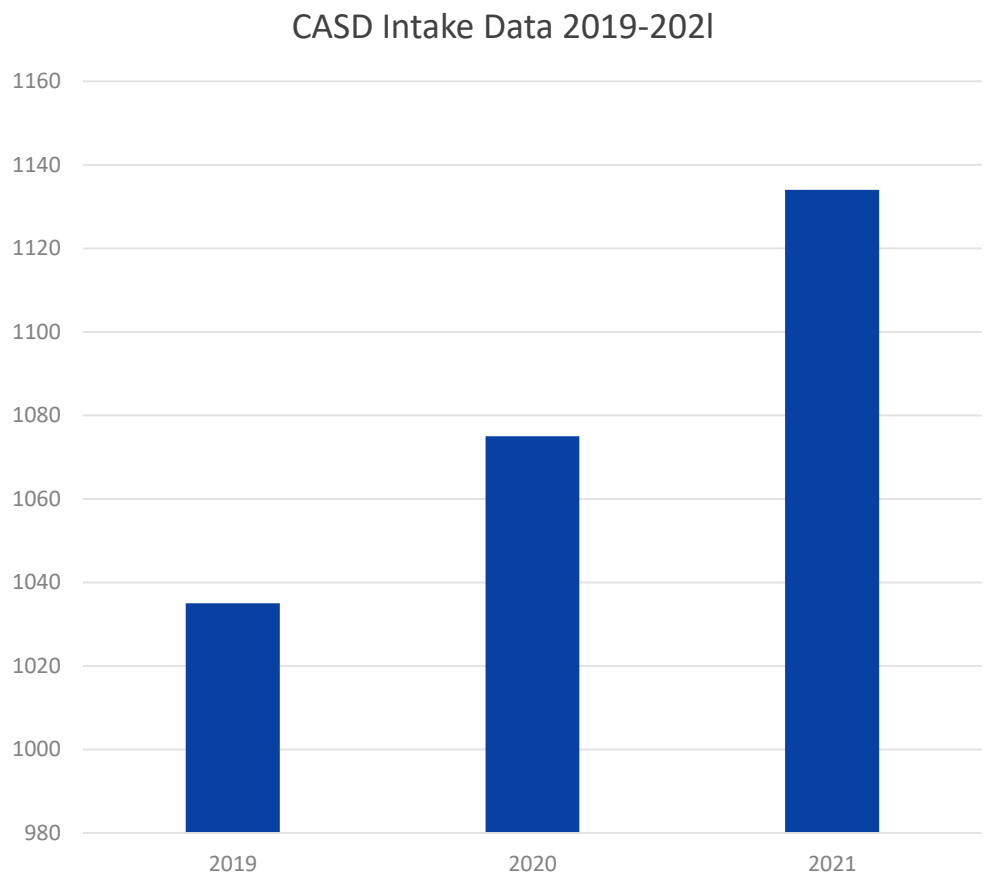
CN's Center for Autism Spectrum Disorder (CASD)





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Referral Practices must be considered

Which children can be reliably diagnosed with ASD without specialist evaluation?

GREEN- "waiting room diagnosis": traits unambiguously consistent with ASD → Diagnose in PCP clinic ideally with structured instrument, and refer for full assessment

YELLOW- Less pronounced ASD traits, more complex differential → Express concerns for potential ASD-related behaviors, refer for specific ASD-related interventions, and refer for full assessment

RED- Very complicated history or differential → Refer for full ASD assessment

Missouri Autism Care Initiative. Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment. https://autismguidelines.dmh.mo.gov/pdf/Guidelines.pdf

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ASD Phenomenology

ASD presentation across development

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ASD Presentation - Infants and Toddlers

Behavioral Characteristic	Disruption 1st reported at 6-12mths	Disruption 1st reported at 9-14mths	Disruption 1st reported at 20-24mths
Social Responsiveness	Poor EC; infrequent looks to others' face; gaze aversion	Abnormal orienting to name; infrequent monitoring of others' gaze	Lack of imitation; lack of interest in other children; infrequent social gaze in response to other's distress
Social Inhibition	Poor social initiative	Infrequent initiation of joint attention and communicative bids for social or regulatory purposes	Infrequent seeking to share
Social-emotional interaction	Absence of facial expression; decreased frequency of smiling	Infrequent sharing of positive affect	Limited range of facial expression; infrequent offering of comfort
Communication and Play	Delay in babbling; decreased frequency of vocalization	Speech delays; reduced variety of play acts, themes, and gestures	Failure to integrate gaze with other communication bxs; abnormal prosody
Sensory, Motor, or Attention Behavior	Hypotonicity; poor motor coordination; abnormal pattern and focus of attention	Repetitive and perseverative actions; difficulty with attention disengagement; unusual sensory response	Repetitive behavior and restricted interests

Landa, R. et al., 2008

ASD Presentation – Early Childhood

Social/Communication Deficits

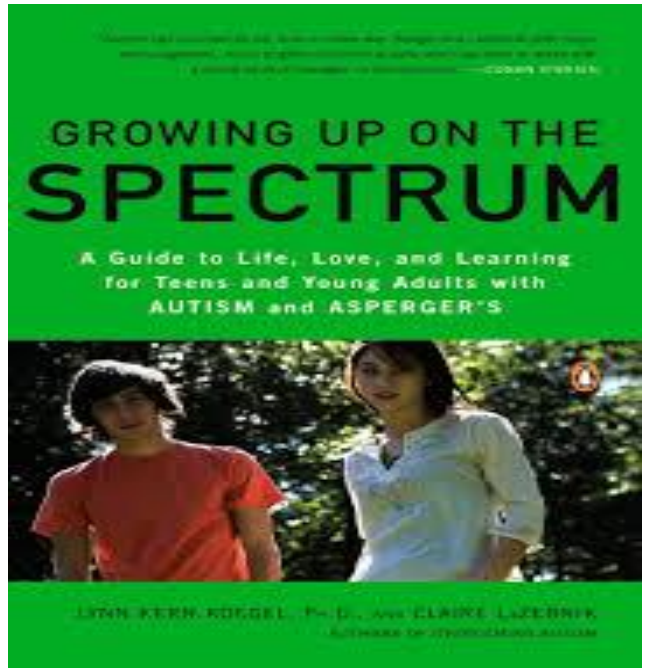
- Language delays or atypicality
- Nonverbal communication (decreased and atypical)
- Reduced social responsivity

Restricted Interests/Repetitive Behaviors

- Echolalia/idiosyncratic language
- Inflexible adherence to specific routine
- Atypical interest in objects (including bias for objects)
- Limited functional use of toys and lack of imaginative play
- Repetitive play and restricted interests
- Sensory regulation differences

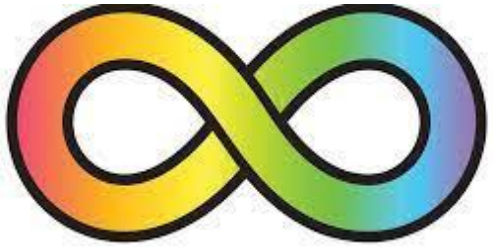
ASD Presentation - Childhood/Adolescence

- Growing social differences
- Learning and executive function problems
- Emotional difficulties
- Compulsive behavior, rituals, difficulty with transitions
- Core and pragmatic communication deficits
- Idiosyncratic language/echolalia
- Sensory regulation challenges
- Greater risk for victimization
- Greater risk for comorbidities



Variability in ASD Presentation

- Uneven skills as significant as delays
- Some girls present with subtle features of ASD which makes recognizing ASD symptoms more challenging in girls
  - **More socially savvy**
  - **Integrate scripted language well**
  - **Good at "camouflaging"**
  - **Interests can be typical, but intense**

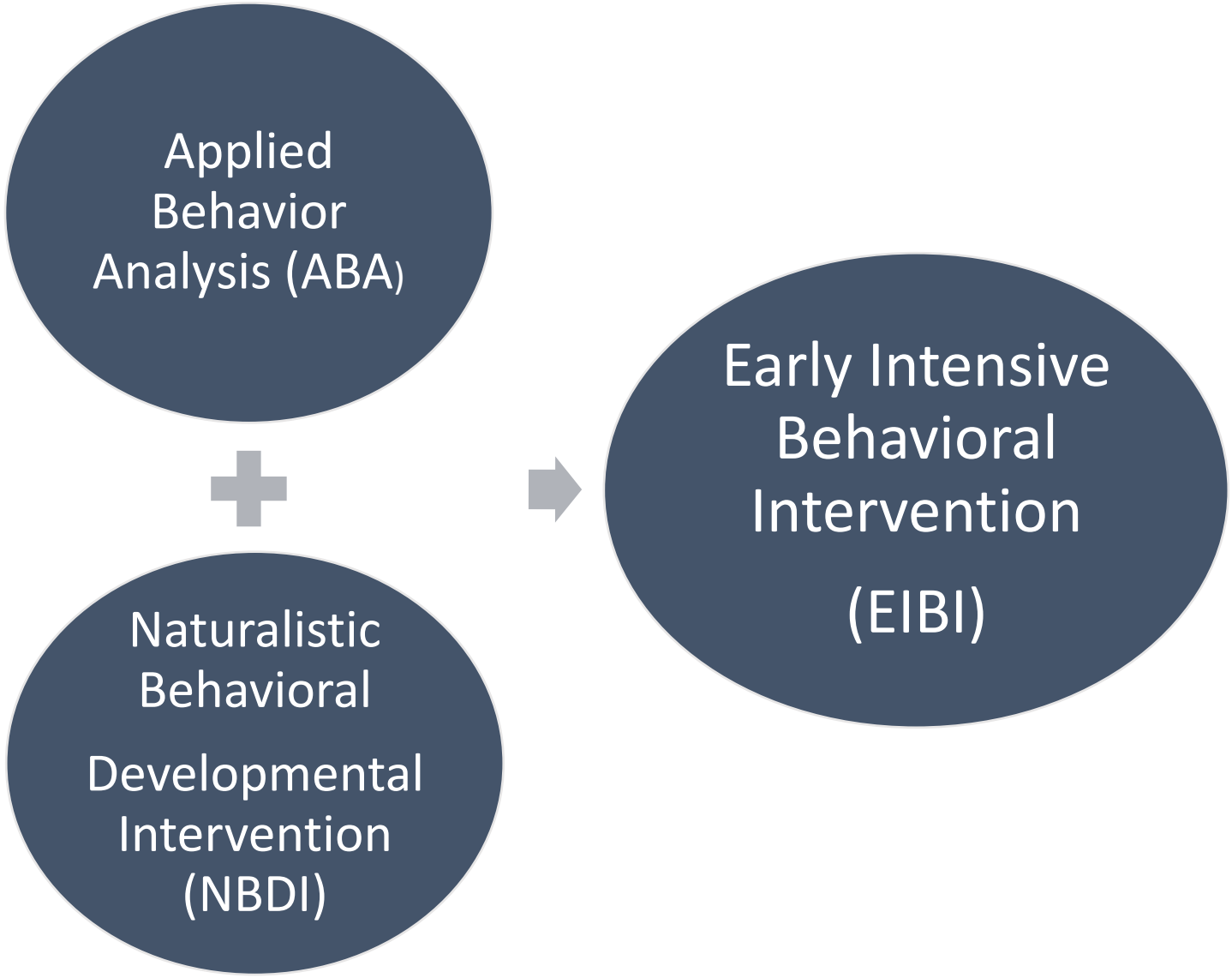


- Autism and gender diversity
  - **Recognized overlap of autism and gender diversity such that screening for gender diversity is recommended in children with ASD**

Evidenced Based Treatment Interventions for Autism Spectrum Disorder

Early Intensive Behavioral Intervention (EIBI)

- Standard of Care for Children < 5 years of age
- 20-30 hours per week
- Specific curricula may vary


Applied Behavior Analysis (ABA)
Naturalistic Behavioral Developmental Intervention (NBDI)
Early Intensive Behavioral Intervention (EIBI)

Evidenced Based Treatment Interventions

ABA

PREMISE

- Behavior/Learning is reinforced or discouraged

EXAMPLES:

- Discreet Trial Training
- Pivotal Response Training

NDBI

PREMISE

- Typical developmental sequences are also observed in children with ASD
- Children learn by actively engaging with their environment
- Skills learned at one developmental level support the transition to more advanced developmental levels

EXAMPLES:

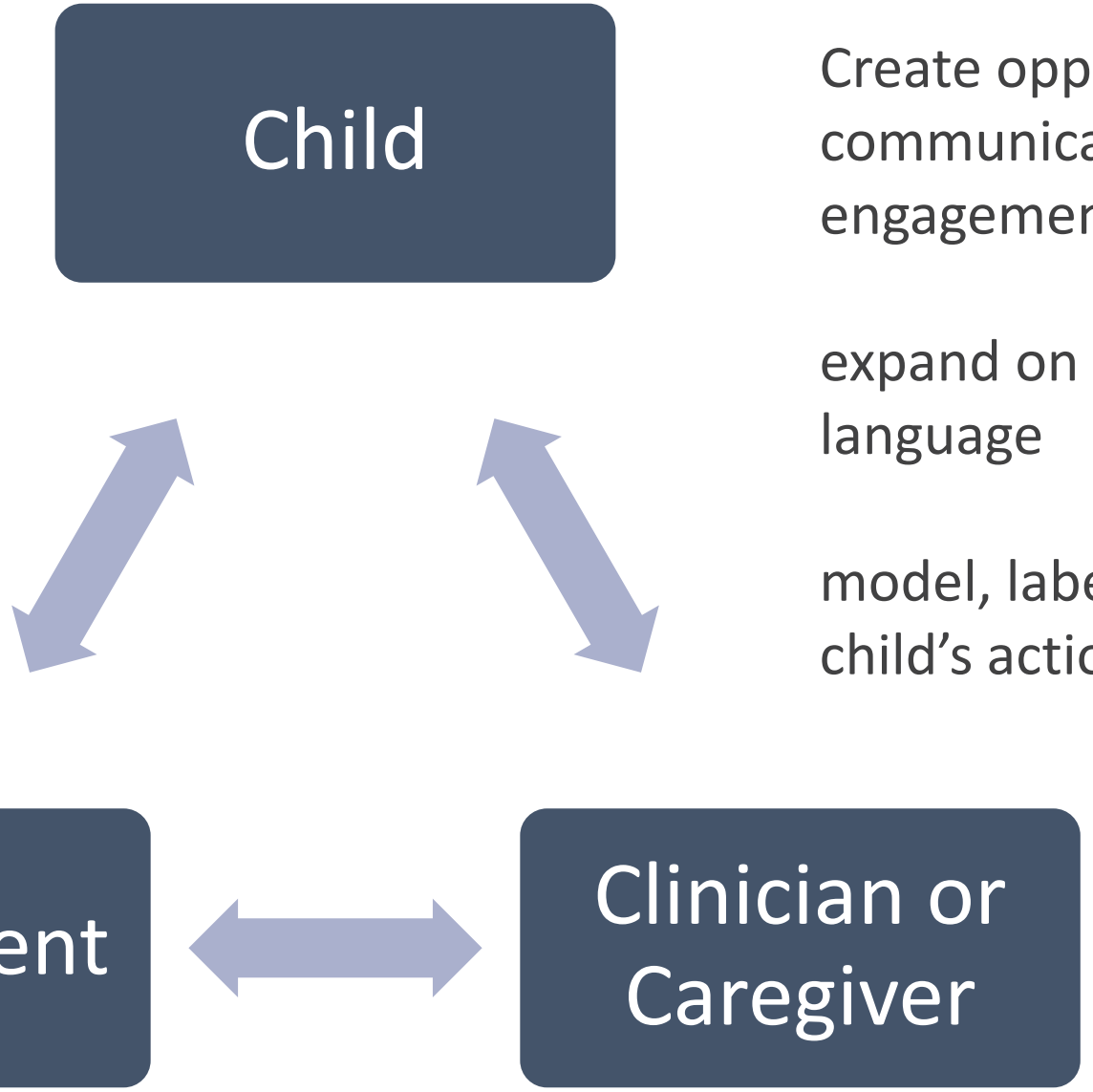
- Denver Start
- LEAP
- Early Achievement

Understanding ABA is as easy as “ABC”

ABA aims to understand behavior through systematic evaluation of what comes before a behavior (antecedents) and what comes after (consequences).

NDBI

Delivery in natural contexts
Shared control between the child and clinician/caregiver
Uses behavioral principles/natural contingencies considers all aspects of a child's development.



Create opportunities for communication and social engagement

expand on child's play and language

model, label and imitate child's actions

Early Intensive Behavioral Intervention (EIBI)

Share common principals

- Data driven
- Incorporate developmental models and applied behavior analysis
- Grounded in knowledge of child development
- Remediate skill deficits
- Replace detrimental behavior with more adaptive behavior

Choosing the right program

Consider family factors (priorities, beliefs)

ABA: may be suited for children who need more structure and predictability

NDBI: may be suited for children who offer leads to follow, who prefer verbal versus visual instruction or who are motivated by social reinforcers

Other Interventions

Speech Language Therapy

- Schedules
- Modeling
- Language Training (Production)
- Scripting

Cognitive Behavioral Therapy

Social Skills (PEERS Program for the Education and Enrichment of Relational Skills) – for adolescents with high functioning ASD

Occupational Therapy

Screening for Autism Spectrum Disorder

Screening for Autism Spectrum Disorder

Developmental Surveillance at all visits

Autism specific screening

- 18 months
- 24 months

Screening for Autism Spectrum Disorder

Level I Screening – screen the general population for ASD symptoms

MCHAT R/F (Modified Checklist for Autism in Toddlers)

Level II Screening – differentiate autism from other developmental disorders

STAT – Screening Tool for Autism in Toddlers (24-36 months)

SCQ (Social Communication Questionnaire)

Social Responsiveness Scale – Second Edition (SRS-2)

Level I Screening

Instrument	Age	Description
MCHAT R/F	16-30 months	Parent Questionnaire/Free Multiple languages (0.91/0.95) 0-2 low risk – no need to do F/U 3-7 moderate risk – Administer F/U to decrease false positive results (increase PPV) 8-20 high risk – bypass follow up and refer

Higher Likelihood of ASD Diagnosis

Primary care provider concern for ASD

Positive MCHAT –R/F screen

ASQ-3 Communication and Personal Social delays

REF: Associations Among Referral Concerns, Screening Results, and Diagnostic Outcomes of Young Children Assessed in a Statewide Early Autism Evaluation Network

Evaluation

Enhancing the PCP Toolkit

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Components of ASD Assessment

- **Comprehensive clinical interview** including review of developmental history and current symptoms
  - Careful attention to onset
  - Focus on core and qualitative features of communication, social development and play
  - Repetitive interests and behaviors including flexibility
  - Sensory seeking and aversive behaviors
- **Standardized observation and interaction** with the child by an experienced clinician
    - *elicited behaviors within an interpersonal context*
- **Developmental anchoring***
    - Cognitive, Language, adaptive functioning

- 24-36 months of age
- Requires completion of web-based training and post-test for certification

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

STAT Overview

- 12 items across domains of:
  - Play
  - Imitation
  - Communication
    - **Directing Attention**
    - **Requesting**
- 20 minutes to administer
- Designed to be flexible (materials, sequence of item presentation, repeating presses)
- Score: Pass, Fail, Refuse
- Provides *risk* indicator for ASD

Published: December 2004

Psychometric Properties of the STAT for Early Autism Screening

Wendy L. Stone, Elaine E. Coonrod, Lauren M. Turner & Stacie L. Pozdol

Journal of Autism and Developmental Disorders **34**, 691–701 (2004) | Cite this article

Use of the Screening Tool for Autism in Two-Year-Olds (STAT) for children under 24 months: An exploratory study

Wendy L. Stone, Caitlin R. McMahon, Lynnette M. Henderson

First Published September 1, 2008 | Research Article | Find in PubMed
https://doi.org/10.1177/1362361308096403

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STAT Training Opportunities

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TREATMENT & RESEARCH INSTITUTE FOR AUTISM SPECTRUM DISORDERS

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STAT-MD Training

Early identification of ASD for pediatric health care providers

STAT-MD Training is designed to teach enhanced diagnostic consultation and screening procedures to pediatric medical providers serving young children. These two-day workshops provide training in conducting autism-focused assessments with children between 18 and 36 months of age. Training components include:

- Performing interactive screening with the Screening Tool for Autism in Toddlers and Young Children (STAT)
- Conducting developmentally sensitive caregiver interviews
- Formulating diagnostic impressions and communicating them to caregivers
- Identifying appropriate billing and coding procedures

Overview

This program was developed through a partnership of the Vanderbilt Kennedy Center's Treatment and Research Institute for Autism Spectrum Disorders (TRIAD), the Tennessee Chapter of the American Academy of Pediatrics, and the Vanderbilt Kennedy Center Leadership Education in Neurodevelopmental and Related Disabilities (LEND), in response to AAP guidelines mandating ASD screening at 18 and 24 months. While many tools are widely available for preliminary screening, waits for appropriate diagnostic services and early intervention services following positive screens are often in excess of 6-12 months. The STAT-MD program provides a mechanism for pediatric clinicians to incorporate diagnostic consultation into their own practices within a time sensitive framework (i.e., 1 hour expanded consultation).

Preliminary evaluation results of this training program have been published in the Journal of Developmental & Behavioral Pediatrics. Findings suggest that incorporating enhanced diagnostic screening based on the STAT-MD model can help accurately identify approximately 3/4 of young children with autism referred for evaluation.

Currently, the Vanderbilt team is expanding this training model, with trainings in West and East Tennessee, in order to develop a state-wide network of pediatricians capable of identifying autism concerns and initiating appropriate early intervention services without prolonged waits.

STAT-MD trainings are offered at Vanderbilt and STAT-MD trainers are available to provide training on site to specific practices. CME credits (up to 13.0 hours) will be provided through the Vanderbilt University School of Medicine for on-site trainings.

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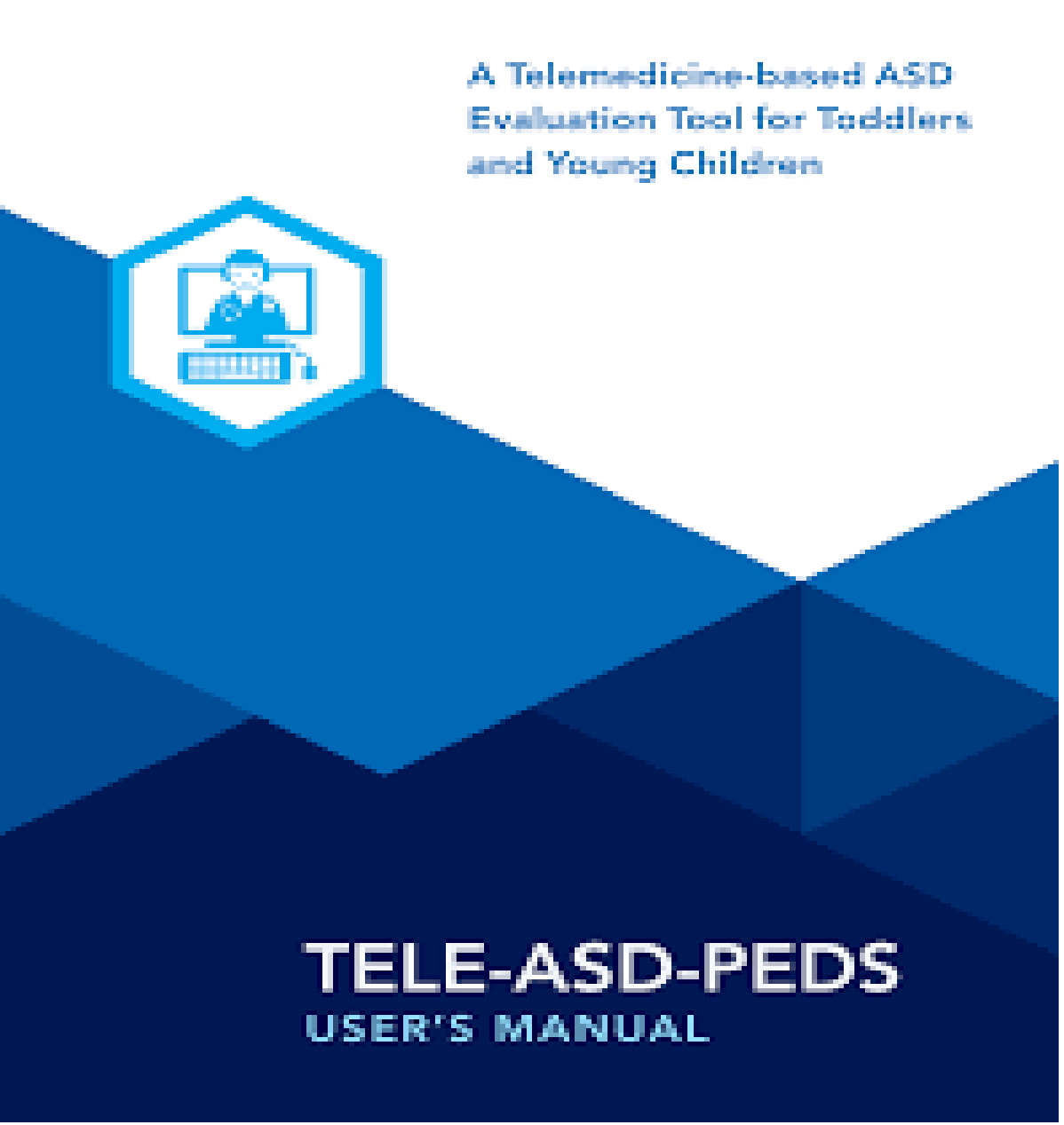
https://vkc.vumc.org/vkc/triad/training/stat/physicians/



Overview

- **FREE!!!!!**
- Designed for at-risk kids under 36 mos; down to 14mos
- May not be appropriate for children with flexible phrase speech
- Not using currently with kids who are not walking, have medical complexities that would complicate the diagnosis (e.g., visual or hearing impairments), have a complex trauma history, or are not living with a familiar caregiver.

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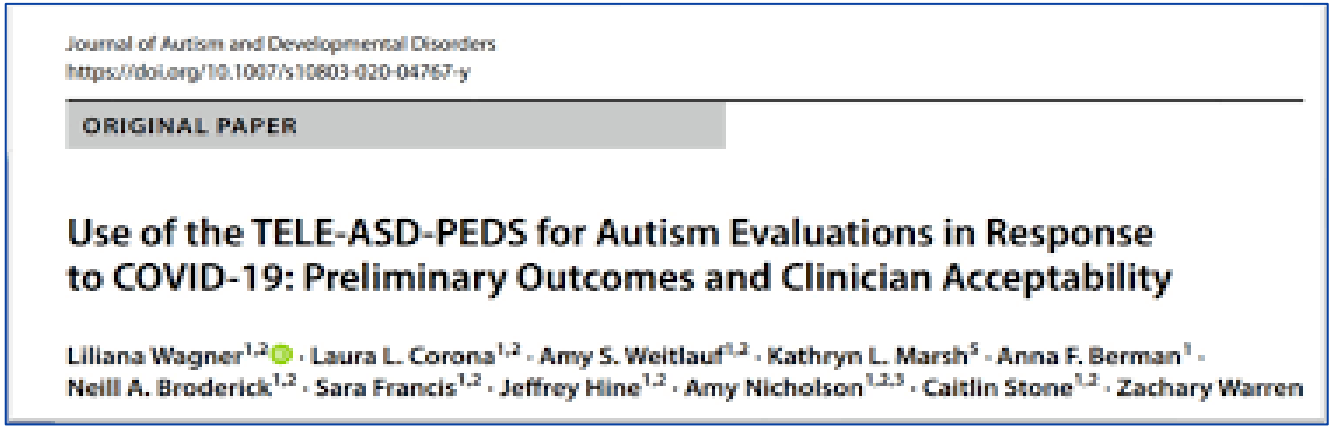
Components

- Toy play (child directed)
  - Responding to social bids
- Toy play (parent-child)
  - Responding to social bids
- Physical Play (tossing, chasing, tickling)
- Requesting (bubbles)
- Ready-set-go play (balloon, car, ball)
- Snack
- Ignore/Close

Psychometrics

- Establishing psychometric properties is one of the aims of Vanderbilt's ongoing clinical trial
- Reliability relative to comprehensive evaluation has been assessed
  - Feasibility study (N=20)
  - 75% dx with telediagnostic
  - 100% agreement


Journal of Autism and Developmental Disorders
https://doi.org/10.1007/s10803-020-04767-y

ORIGINAL PAPER

Use of the TELE-ASD-PEDS for Autism Evaluations in Response to COVID-19: Preliminary Outcomes and Clinician Acceptability

Liliana Wagner[1,2] · Laura L. Corona[1,2] · Amy S. Weitlauf[1,2] · Kathryn L. Marsh[5] · Anna F. Berman[1] · Neill A. Broderick[1,2] · Sara Francis[1,2] · Jeffrey Hine[1,2] · Amy Nicholson[1,2,3] · Caitlin Stone[1,2] · Zachary Warren

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Want more info?

1. Go to **triad.vkclearning.org**
2. Create a free account by clicking on **"Register."** You will create a username and password. Fill out the form and select **"TRIAD"** under the doorway. You will receive an email verification. Once you do, click the link to verify your account and log in.
3. Choose **Telehealth Resources** logo
4. Click **"open"** next to **"Telemedicine-based ASD Assessment in Toddlers (TELE-ASD-PEDS)"**

Decision Making

When to Refer?

GREEN- "waiting room diagnosis": traits unambiguously consistent with ASD → Diagnose in PCP clinic ideally with structured instrument, and refer for full assessment

YELLOW- Less pronounced ASD traits, more complex differential → Express concerns for potential ASD-related behaviors, refer for specific ASD-related interventions, and refer for full assessment

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Missouri Autism Care Initiative. Autism Spectrum Disorders: Missouri Best Practice Guidelines for Screening, Diagnosis, and Assessment. https://autismguidelines.dmh.mo.gov/pdf/Guidelines.pdf

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Where to Refer?

GREEN- "waiting room diagnosis": traits unambiguously consistent with ASD

YELLOW- Less pronounced ASD traits, more complex differential

RED- Very complicated history or differential

- **Consider:**
  - **AGE**
  - **COMPLEXITY**
- **When complex or older – Psychological testing is recommended**
- **Simultaneous referral to Neurodevelopmental Pediatrics when involves medical complexity**
- **Consider waitlists and explain this to families**

Referral Resources

- Children's National
  - Neurodevelopmental Pediatrics Clinic, **202-476-2327**
  - Child Development Clinic, **202-476-5405**
  - Center for Autism Spectrum Disorders, **301-765-5430**
- Outside Children's National
  - Mt Washington Autism Spectrum Center, **410-367-2222**
  - KKI Center for Autism and Related Disorders, **443-923-7630**
  - Georgetown Autism and Communication Disorders Clinic, **202-444-2722**
- Community-Based
  - https://referral.mditp.org/
  - https://www.itcva.online/
  - https://osse.dc.gov/service/strong-start-dc-early-intervention-program-dc-eip

Differences among CNH referral options

	Developmental Pediatrics	Child Development Clinic	Center for Autism Spectrum Disorders (CASD)
Staff	Developmental pediatricians (MDs/NPs)	Developmental/clinical psychologists	Multidisciplinary (neuropsych., psychologists, SLPs, MDs, etc.)
Ages served	Birth through early adulthood	Birth to 3½ years	12 months through early adulthood
Provides:	• Developmental/ medical monitoring • Medication treatment	Psychosocial perspective, Assessing broader development	• Neuropsychological evaluation across age, cognitive, & language levels • Research Focus: Executive Function-Based Treatments across child and young adulthood; Gender & autism intersection; Girls and young women with ASD • Evidenced-Based Group & Individual Treatment services • Provider resources including ECHO Autism Clinics; Family Supports
Waitlist	Waitlist – Varies; 6-9mos	Waitlist = ~4mos	Waitlist = Varies; 1-2 years for most services

Case vignette (18m WCC)

18-month-old boy comes in for a well-child visit

Immature language: says ‘mama’ and ‘dada’ but no other words

Receptive language: “he understands everything”

Gesture use: waves ‘bye’ and reaches towards objects but doesn’t point with an isolated finger

Eye contact: seems reduced during the session, but parents describe EC as better at home

Social: seems object-focused, less oriented towards people

Motor development is appropriate; no concerns around feeding/sleep/etc.

M-CHAT of 3

Case vignette (18m WCC, cont.)

How can we dig deeper to determine whether a referral might be indicated, given the time limitations?

Clarifying social communication deficits:

How does he let you know what he wants (i.e., object out of reach)?

- Try to elicit a wave (or other imitative gesture)
- Pointing with coordinated EC vs. reaching/fussing towards object
- Making use of EC to plead vs. focusing on object
- Does he follow a point?

Case vignette (18m WCC, cont.)

How can we dig deeper to determine whether a referral might be indicated, given the time limitations?

Clarifying receptive language:

- Does he respond to his name?
- Can he point to body parts on request

Case vignette (18m WCC, cont.)

How can we dig deeper to determine whether a referral might be indicated, given the time limitations?

Clarifying social functioning

What types of games/activities can elicit a smile? (Peekaboo, etc)

What does he do if parents leave the room? Upset if left alone with unfamiliar clinician? Excited/relieved upon reunion with parents? (Gesturing to be picked up)

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Case vignette (3y WCC)

A girl comes in for a 3-year-old well-child visit

She hasn't been seen for an in-person visit since 2019

The diagnosis seems clear: no EC, numerous red flags/RRBs (hand-flapping, toe-walking, spinning), does not orient to people, does not respond to her name, etc. She also has broader delays (no words, failed ASQ).

The family has missed numerous appointments in the past. How can we get her the most services quickly and feel assured that she won't fall through the cracks.

Do pediatricians feel comfortable making the diagnosis?
How would they talk to the family about the autism diagnosis?
…about why it would be important to make use of the diagnosis at "such a young age"?

What referrals would you make?
Special education preschool, referral to ASD specialist

Case vignette (3y WCC) cont.

Are their other factors that could impact how to approach getting services started?

Jurisdictions: DC vs. higher-income counties vs. lower-income counties

ABA therapy
How to help families access ABA?
Through early intervention/public school system
Through their health insurance
Calling clinics directly

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Resources

Resources for Providers

To Learn more about Early Signs of ASD

- KKI Early Signs of Autism Video Tutorial
- Autism Navigator

ASD Evaluation/Training:

- STAT
- ASD-PEDS
- CN ECHO Autism Program

Resource Navigation:

- www.pathfindersforautism.org
- HealthCheck: DC Child and Adolescent Mental Health Resource Guide (dchealthcheck.net)
- https://www.autismspeaks.org/resource-guide
- https://referral.mditp.org/
- https://www.itcva.online/
- https://osse.dc.gov/service/strong-start-dc-early-intervention-program-dc-eip
- https://childrensnational.org/departments/gender-development-program/gender-and-autism-program

ECHO Autism at Children's National

Moving **knowledge,** not **people**

Children's National

Project ECHO

ECHO AUTISM COMMUNITIES

Pediatric Health Network

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ECHO AUTISM, hosted by CN's Center for Autism Spectrum Disorders, creates a virtual learning network that aims to "move knowledge, not patients" using a telementoring format that provides access to a hub of medical experts to support community providers to diagnose, treat and care for ASD children and their families

HOW IT WORKS

- Convenient, **web-based** small-group format
- Learn and share **best practices** for autism care, connecting with community resources, and family/caregiver support
- **Reduce costs** for families and providers by limiting travel, creating **more efficient visits and shorter wait times for care**
- Provides a long-term solution in communities, including underserved areas where access to autism specialists is limited, by **building local capacity** for autism care

SCHEDULE:

- **Primary Care Clinic:**
- **January-June 2022 1st/3rd Friday, 12-1:00PM**

BENEFITS:

- **Free CE hours**, 2 hours, monthly
- Real-time **case guidance** with multidisciplinary team of autism experts
- Meet a **network of other providers** handling similar challenges

WHAT YOU NEED TO START:

- Internet connection + Front-facing camera, smartphone or tablet
- Commitment to 1-1.5-hour learning sessions

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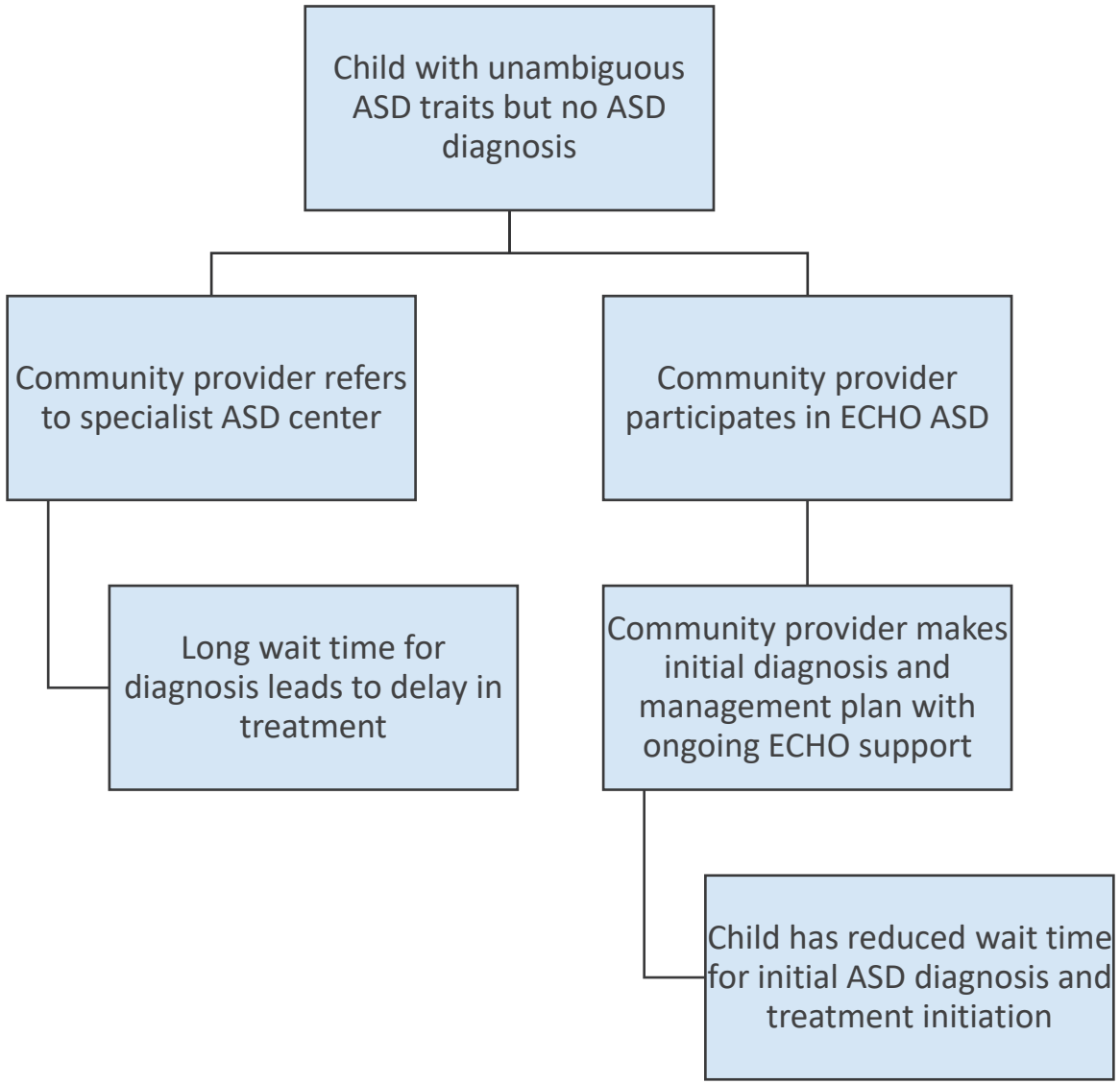

Original Paper | Published: 24 July 2018

ECHO Autism STAT: Accelerating Early Access to Autism Diagnosis

Micah O. Mazurek, Alicia Curran, Courtney Burnette & Kristin Sohl

Journal of Autism and Developmental Disorders **49**, 127–137 (2019) | Cite this article

3309 Accesses | **36** Citations | **37** Altmetric | Metrics

ECHO Autism: A New Model for Training Primary Care Providers in Best-Practice Care for Children With Autism

Micah O. Mazurek, PhD, Rachel Brown, MBBS, Alicia Curran, BS, more... Show all authors

First Published May 11, 2016 | Research Article | Find in PubMed | Check for updates

https://doi.org/10.1177/0009922816648288

Image courtesy of Dr. Kelly Register-Brown

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Interest/Questions?

Contact:

ECHO Coordinator: Chelsea Armour
aarmour@childrensnational.org

ECHO Lead Facilitator: Annie Inge

ainge@childrensnational.org

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Resources for Families

To Learn more about Early Signs of ASD

- CDC LSAE: https://www.cdc.gov/ncbddd/actearly/index.html
- Baby Navigator: https://babynavigator.com/
- Autism Navigator: https://autismnavigator.com/
- KKI Early Signs of Autism Video Tutorial: https://www.youtube.com/watch?v=YtvP5A5OHpU

Parent Training:

- Vanderbilt Families First: https://vkc.vumc.org/vkc/triad/fam/
- Hanen: http://www.hanen.org/Programs/For-Parents.aspx
- Koegel PRT Parent Training: https://education.ucsb.edu/autism/treatment/multiday-program
- Early Start Denver Model: https://www.esdm.co/attendworkshop

Resource Navigation:

- www.pathfindersforautism.org
- https://www.autismspeaks.org/resource-guide
- Dc autism parents
- POAC nova
- Xminds.org
- www.ppmd.org

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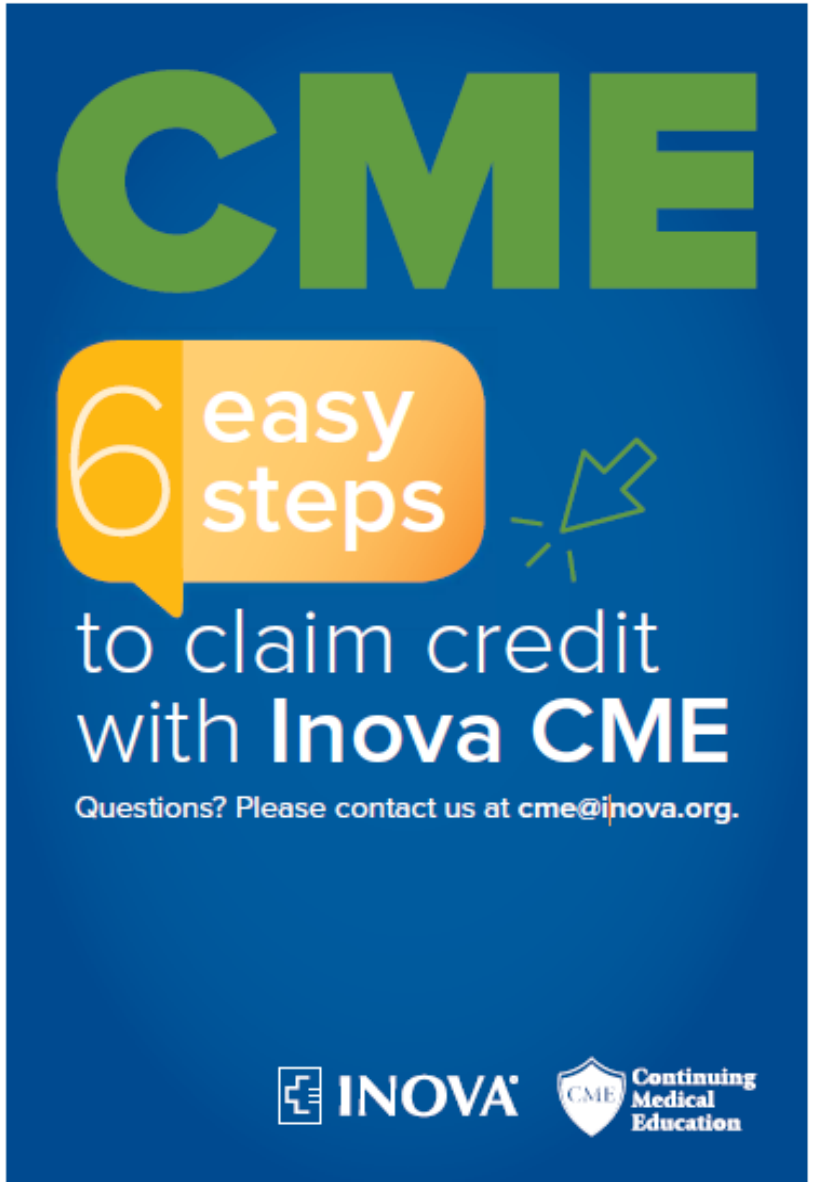

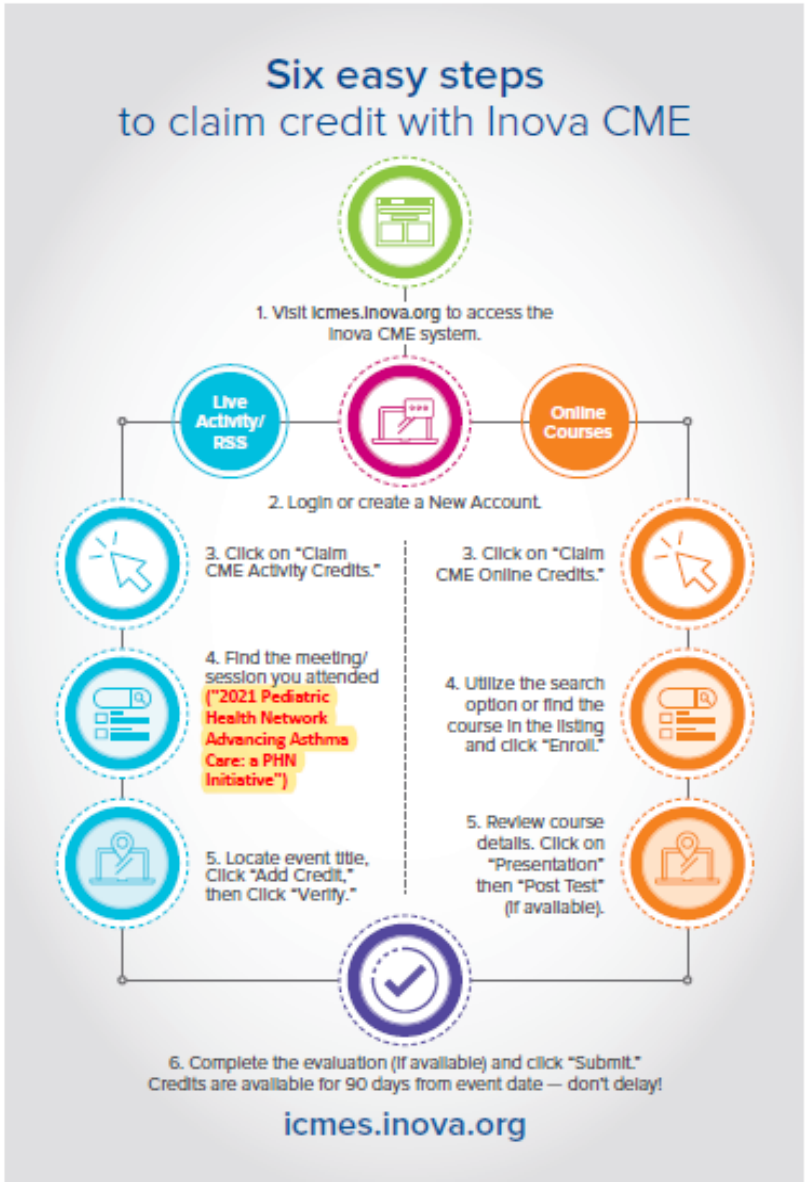

- ✓ CME must be claimed within **90 days** of event!

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Thank you

PHN@childrensnational.org