



Enhanced Support to PCPs in the Identification and Treatment of Autism Spectrum Disorders

Melissa Long, MD, Amanda Hastings, PsyD, BCBA, Leandra Godoy, PhD,
Annie Inge, PhD, Kelly Register-Brown, MD

Team Acknowledgements

Primary Care Team: Lee Beers, Cara Biddle, Erica Eisenman, Michael Geraldo, Serene Habayeb, Amanda Hastings, Annie Inge, Tona Jackson, Maria Lauer, Melissa Long, Donna Marschall, Xavier Marshall, Hope Rhodes, Sharon Singh, and Renee Williams

ECHO Team: Chelsea Atmore, Amanda Hastings, Annie Inge, Shaline Khurana, Colleen Morgan, Yetta Myrick, Lori Kraden, Kelly Register-Brown and Allysa Ware

Additional Contributors: Sarah Barclay-Hofman, Sarah Bernstein, Yetta Myrick, Alison Page, Shaakira Parker, Elyssa Sham, Olivia Soutullo, Pennie Theodorou,

Departments: CHAI, Division of Psychology & Behavioral Health, Goldberg, Whole Bear Care, Center for Autism Spectrum Disorders

Disclosures

No conflicts to disclose:

- No financial or business interest, arrangement or affiliation that could be perceived as a real or apparent conflict of interest in the subject (content) of their presentation.
- No unapproved or investigational use of any drugs, commercial products or devices.

Speaker Bios



Leandra Godoy, PhD

Psychologist

Takoma Theatre &
Children's Health
Center- Shaw Metro



Amanda Hastings, PsyD, BCBA

Psychologist

Children's National- Takoma
Theatre



Melissa Long, MD

Pediatrician

Children's Health
Center – Shaw Metro

Learning Objective

Describe **resources and innovative practices** that can aid PCPs in better identifying and managing children with Autism Spectrum Disorders (or suspected ASD)



Resource



*Food for
Thought/
Did you Know*

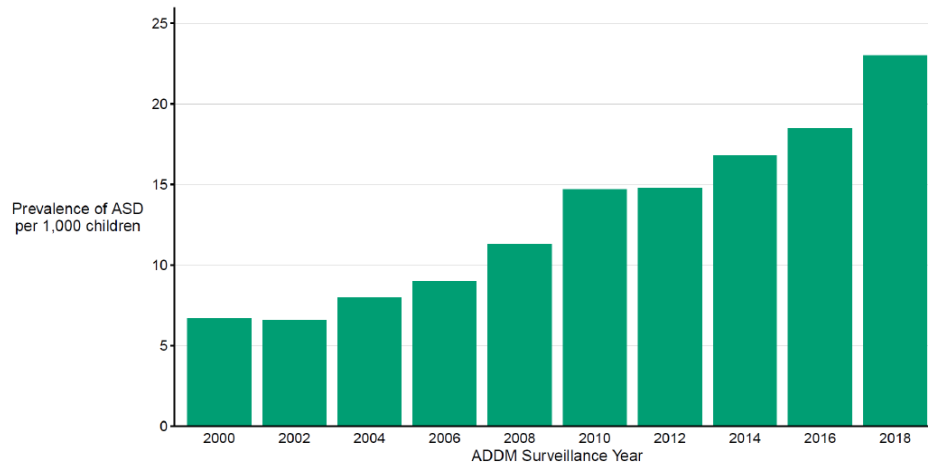
Scope of the Problem

ASD prevalence is growing (1:1000 in 1980's → 1:44 today)

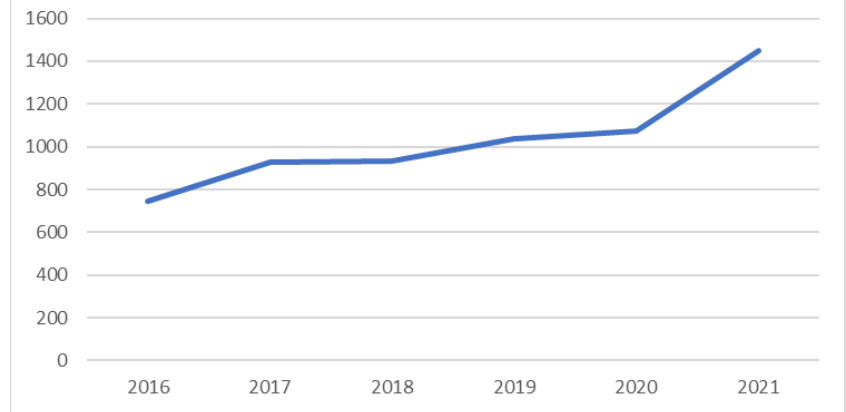
Integrated ASD screening more common but challenges in connecting with evaluations & services

- Long waitlists (>1-2 years!)

Prevalence of autism spectrum disorder per 1,000 children aged 8 years, by surveillance year
Autism and Developmental Disabilities Monitoring Network, 2000–2018

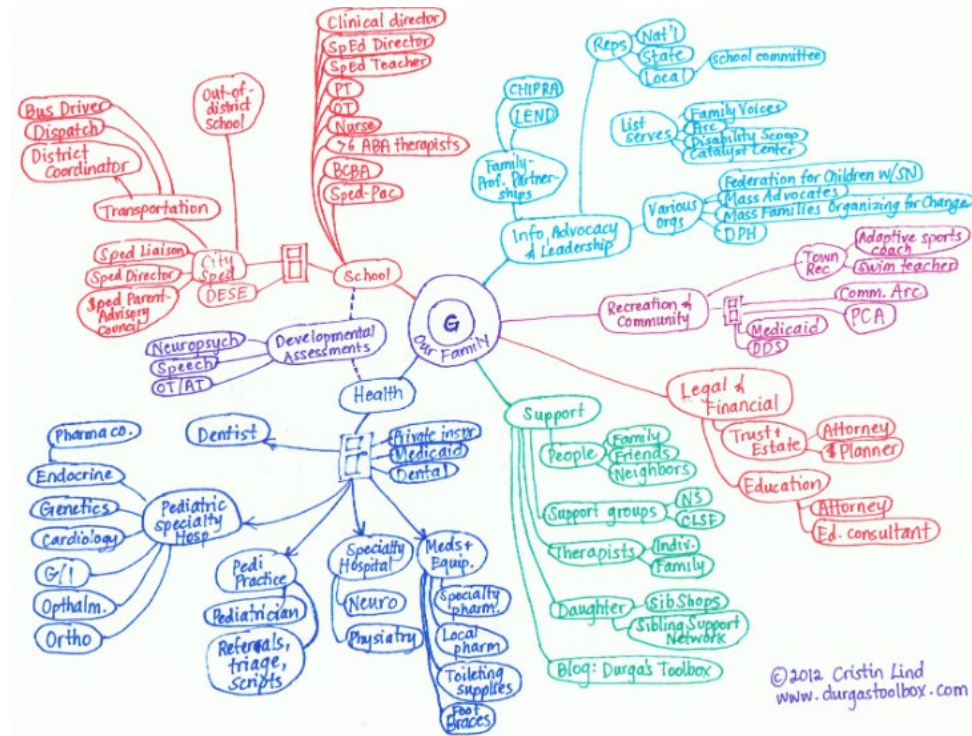


CASD Intake Data 2016-2021



Scope of the Problem

- Confusing systems of care
- Barriers to care (e.g., insurance)
- Inequities in care (ELL, low health literacy, Medicaid)



Overview



CNH Neurodevelopmental Landing Page



Children's National

 Find a Doctor

Donate



For Healthcare Providers



Refer a Patient



Clinic Guidelines

Autism and
Neurodevelopmental

Diagnostic Imaging and
Radiology

Autism and Neurodevelopmental Referral Guidelines

Share:     

Children with neurodevelopmental concerns need specialized testing, diagnosis and treatment, as well as comprehensive care coordination to achieve the best outcomes. Learn about our related referral guidelines.



Child Development Clinic (Ages 0-3)



Neurodevelopmental Pediatrics (Ages 0-21)



Center for Autism Spectrum Disorders (CASD) (Ages 1-26)



Autism Behavioral Consult Service (Ages 0-22)



General Neuropsychology Service (Ages 4-22)



<https://childrensnational.org/healthcare-providers/refer-a-patient/referral-guidelines/autism-and-neurodevelopmental-referral-guidelines>

Navigating Neurodevelopmental Referrals at Children's National

	Neurodevelopmental Pediatrics	Child Development Clinic	Center for Autism Spectrum Disorders (CASD)
Provider Type	Developmental pediatricians (MD/DO/NP)	Developmental/clinical psychologists (PhD/PsyD)	Multidisciplinary [(neuro)psychologists, psychologists, SLPs, psychiatrist, etc.]
Age Range	Birth through early adulthood	Birth to 3½ years	12 months through early adulthood
Services Offered	<ul style="list-style-type: none"> Evaluations for delays in development Some providers will do ADOS Treatment / medication DOES NOT provide comprehensive IQ testing or neuropsychological evaluations. 	<ul style="list-style-type: none"> Developmental evaluations assessing cognitive, language, motor, adaptive, attention/self-regulation and social/emotional functioning ASD evaluations (including the ADOS) NICU follow-up 	<ul style="list-style-type: none"> Standalone and multidisciplinary assessments Diagnostic, Neuropsychological, and Developmental assessments Individual and group therapy

Tips for Navigating Referrals (& Waitlists)

Referral considerations regardless of ASD dx status



- Early Intervention or school-based eval
- Audiology
- Speech Therapy
- Occupational Therapy
- Care coordination through insurance
- Other specialty providers (e.g., sleep, neurology)

*Strong Start does
not evaluate for
ASD*

Dual eval referrals are encouraged

El/School-
Based

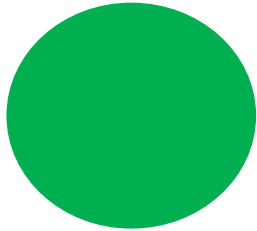
Specialty
Medical



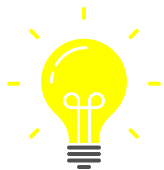
*Medical dx & edu classification
of ASD, not interchangeable &
do not always align*

Tips for Navigating Referrals (& Waitlists)

Refer for ASD medical evaluation even if dx is clear to assist with authorizations (e.g., ABA) & overall treatment planning



*Unambiguous ASD
(e.g., IEP says
Autism)*



*PCPs **can** diagnose ASD
(but certain testing may
be required to access
certain txs)*

Letter of Medical Necessity / Referral

Evaluation and Treatment

Date: _

Patient Name: _

Date of Birth: _

Diagnosis:

1. Autism Spectrum Disorder F84.0
2. Speech Language Disorder F80.9
- 3.
- 4.
- 5.

Therapy / Services being requested:

- ☒ Speech and Language (Evaluate/Treat)
- ☒ Occupational Therapy (Evaluate/Treat)
- ☐ Physical Therapy (Evaluate/Treat)
- ☒ Applied Behavioral Analysis (ABA) Therapy
- ☐ Other: _____

Notes/ Pertinent Medical History:

- Please refer to visit summary or full clinic note for details

Therapy Frequency:

- Based on clinical assessment and evaluation of the therapist
- ABA Therapy recommended at least 25 hours/week

ASD Toolkit for PCPs in DC



Home About Trainings Resources Calendar Search Login/Logout

DC HealthCheck Resources

DC Contacts

DC Periodicity Schedule

DC Mental Health Resource Guide

EPSDT Billing Materials

HealthCheck Outreach Materials

General Pediatric Resources

Agencies/Organizations

Cultural/Linguistic Competence

Autism Spectrum Disorders (ASD) Toolkit

The [DC Collaborative for Mental Health in Pediatric Primary Care](#) has created the **Autism Spectrum Disorders Toolkit for Pediatric Primary Care Providers in the District of Columbia**. This toolkit focuses specifically on supporting children with Autism Spectrum Disorders and their families, by providing primary care providers with the tools to help families navigate the developmental disabilities landscape in Washington, DC. The tool includes:

- An overview of ASD.
- Screening guidelines and tools.
- Diagnostic evaluation.
- Referral algorithm.
- Early intervention and school-based services.
- Treatment options.
- Information on Supplemental Security Income and Insurance.
- Local resources.

Al
To
Pr
th
Or

DC
DC
DC
DC
DC



<https://www.dchealthcheck.net/resources/healthcheck/ASD-toolkit.html>

Additional Resources for Providers



Developmental Monitoring, Screening, and Evaluation:

A GUIDE FOR HEALTH AND EARLY EDUCATION PROVIDERS IN DC



Developmental Monitoring/Surveillance

	Health Provider Role & Responsibilities	Early Care and Education Provider Role & Responsibilities	How to Partner with Families
Developmental monitoring or surveillance is an active on-going process of watching a child grow and encouraging conversations between parents and providers about a child's skills and abilities. Developmental monitoring supports and complements (but does not replace) developmental screening.	The Academy of American Pediatrics (AAP) recommends developmental surveillance at all well-child visits. This includes: <ul style="list-style-type: none"> review developmental history; ask about concerns; assess strengths and risks; observe the child; document; and share results with others. Encourage parents to monitor milestones between visits and share results with pediatrician and other providers (i.e., educational providers).	Early Care and Education Providers can: <ul style="list-style-type: none"> Regularly use milestone checklists to monitor a child's development. Encourage families to monitor their child's development at home and share results with educators and health care providers.	Parents can be encouraged to: <ul style="list-style-type: none"> Track their child's developmental milestones at intervals (2, 4, 6, and 9 months, 1 year, 15 and 18 months, 2 years, 30 months, 3, 4 and 5 years using free milestone trackers Share results and concerns with health and education providers
Resources:	AAP's Recommendations for Preventive Pediatric Health Care	CDC's Child Find Primer CDC's Early Care and	CDC's "Learn the Signs. Act Early." Program Materials

Autism Spectrum Disorders						
Modified Checklist for Autism in Toddlers (MCHAT)	16-30 months	Early signs of autism and identify developmental delay	Parent: 20 items	Eng, Span, + other languages	Free	https://www.autismspeaks.org/screen-your-child
Social-Communication Questionnaire (SCQ)	4+ years	Screening for autism spectrum disorders	Parent: 65 items Teacher: 65 items	Eng, Span, + other languages	\$	https://www.wpspublish.com/scq-social-communication-questionnaire#simpleproducts
Social Responsiveness Scale (SRS)	2.5 + years	"Distinguishes autism spectrum conditions from other child psychiatric conditions by identifying presence and extent of autistic social impairment"	Parent: 20 items	Eng, Span, + other languages	\$	https://www.wpspublish.com/srs-social-responsiveness-scale
Autism Spectrum Quotient (ASQ)	4+ years	Measuring the severity of Autism-Spectrum Disorder and utilized for research.	Parent: 50 items Self Report: 50 items	Eng, Span, + other languages	Free	https://www.autismresearchcentre.com/arc_tests
Communication and Symbolic Behavior Scales (CSBS)	6-24 months	"The first step in routine screening to see if a developmental evaluation is needed by examining 7 key predictors of later language delays"	Parent: 22 items	Eng, Span, + other languages	Free	https://brookespublishing.com/product/csbs-dp-its/
Parent Observation of Social Interactions	16-35 months	Used to assess autism risk; ASD screening included on 18-	Parent: 7 items	Eng, Span, + other	Free	https://www.tuftschildrenshospital.org/The-Survey-of-

Current DC Medicaid MCOs Processes and Guidelines Re: Autism Spectrum Disorder Services for Children

<https://childrensnational.org/advocacy-and-outreach/child-health-advocacy-institute/community-mental-health/mental-health-initiatives-and-activities/dc-autism-collaborative>

https://www.dchealthcheck.net/documents/Domain%20Specific%20Screening%20Tools_Rev_01.28.2022.pdf



Tips for Talking with Families

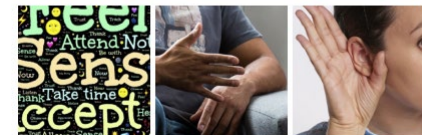
Aims: Parental understanding & shared concerns/goals

- Use the word autism
- Describe how ASD is different from developmental delay and requires a specific intervention approach
- Empower families around next steps
- Answer & encourage questions - dispel myths
- Acknowledge cultural factors
- Give voice to ambivalence (e.g., “he’ll grow out of it”)
- Acknowledge waits for services
- Make a follow up appointment to review results



<https://www.autismspeaks.org/sites/default/files/2018-08/Guide%20to%20Delivering%20Feedback.pdf>

**Provider’s Guide to Effective
Communication with Families
Affected by Autism**



Parent Resources

Coming Soon!

What To Do

While You Are Waiting for a Medical Diagnostic Evaluation for Autism

DC-AC Education, Outreach, Engagement Subgroup
Version 1 Summer 2022



Waitlists to receive a formal medical evaluation for autism are often long which can be frustrating. While a formal medical diagnosis of autism opens up a number of doors to receive certain types of intervention services through your insurance (for example applied behavior analysis[ABA]), there are a number of other steps you can take to support your child's development while you are waiting for this evaluation.

SEEK OUT EARLY INTERVENTION OR SPECIAL EDUCATION SUPPORT:

- ✓ Contact DC's early childhood systems to request a free evaluation to see whether your child qualifies for intervention services. Families can call on their own and do not need a referral from a medical professional. Here are some [tips](#) on what to say when you call.
- If your child is under 3, contact [Strong Start \(IDEA part C\)](#) to complete an evaluation and begin early intervention services.
202-727-3665 | osse.dceip@dc.gov
- If your child is 3 or older contact [Early Stages \(IDEA part B\)](#) to complete an evaluation and to start special education services.
202-698-8037 | referral@earlystagesdc.org

START SERVICES IN AREAS OF NEED:

- ✓ Your pediatrician can refer your child to specialists who can provide therapy services in different areas (speech and language therapy, occupational therapy, physical therapy). Such services should be covered by your health insurance and do not require a formal diagnosis of autism to access them.

CONTINUE TO SUPPORT YOUR CHILD'S DEVELOPMENT:

- ✓ Other professionals can provide lots of support. Remember, YOU know your child best. The following free resources are for parents to use in supporting their child's development:
 - [Help is in Your Hands](#) is an online interactive resource for families with young kids with symptoms of or diagnosed with autism. It is a free website with 16 web-based video modules to help parents add simple methods to their everyday routines at home.
 - [Parent Encouragement Program \(PEP\)](#) offers online and in-person trainings to give parents the knowledge to understand the underlying causes of their children's behavior and the practical skills and tools they need to address problems right away. PEP programs are offered in English and Spanish and include videos-on-demand, webinars, virtual and in-person classes, and individual support.
 - [Caregiver Skills Trainings](#) from Autism Speaks and the World Health Organization is a free online training program that teaches caregiver's day-to-day skills to help boost the wellbeing and development of children ages 2-9 with autism and other developmental delays.



Do you or your child's provider suspects that your child may have an AUTISM SPECTRUM DISORDER?

What Is Autism?

Autism or autism spectrum disorder (ASD) is a neurodevelopmental disability that can be associated with social, communication, and behavioral challenges. Children diagnosed with autism may communicate, interact, behave, and learn in ways that are different from people without autism. You can visit the [Centers for Disease Control and Prevention \(CDC\)](#) autism webpage to learn more about how autism is defined.

How Common Is Autism?

Center for Disease Control (CDC) estimates that about 1 in 44, 8-year-old children have been identified with autism. You can view the [CDC Autism and Developmental Disabilities Monitoring Network's 2021 Community Report](#) to learn more.

How Is Autism Diagnosed?

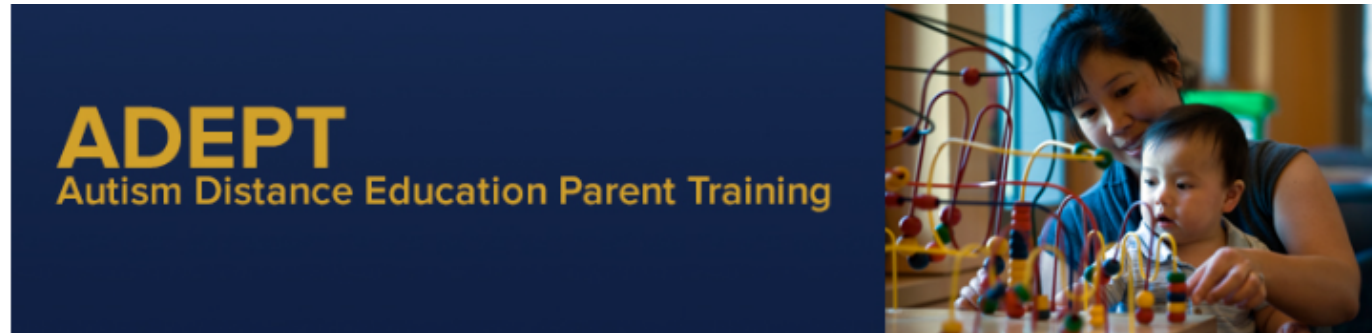
A diagnosis of autism is made based on your description of your child's development, a review of your child's history and observations of certain behaviors by your child's primary care provider and an autism expert. You can learn more by reading the American Academy of Pediatrics' article, "[How Is Autism Diagnosed?](#)"

The criteria for diagnosing autism include:

- ✓ challenges with social communication and interaction
- ✓ restricted or repetitive behaviors or interests



Free Parent Resources: 'While You Wait'



One of the goals of the Center for Excellence in Developmental Disabilities is to provide educational resources on developmental disabilities to the community. To that end, CEDD has sponsored the production of the following educational videos and online training modules.

ADEPT (Autism Distance Education Parent Training) Interactive Learning is an original MIND Institute/CEDD 10-lesson interactive, self-paced, online learning module providing parents with tools and training to more effectively teach their child with autism and other related neurodevelopmental disabilities functional skills using applied behavior analysis (ABA) techniques.

[Accessibility Notes ▾](#)

[Module 1: Strategies for Teaching Functional Skills ▾](#)

[Module 2: Positive Behavior Strategies for Your Child with Autism ▾](#)



[**UC DAVIS ADEPT Training Program: Behavioral skills training for parents of children with ASD \(English, Chinese, Korean, Vietnamese and Spanish\)**](#)

Additional Parent Resources



- **Book:** An Early Start for Your Child with Autism by Sally Rogers, Geraldine Dawson, & Laurie Vismara
- **Online Resources & Trainings**
 - Autism Internet Modules:
<http://www.autisminternetmodules.org>
 - Hanen: <http://www.hanen.org/Home.aspx>
 - Help is in your Hands:
<https://helpisinyourhands.org/course>
 - Vanderbilt Triad:
<https://vkc.vumc.org/vkc/triad/forfamilies>

Children's National Caregiver Webinar Series (Zoom)

12:00pm-1:00pm 3rd Wednesday of month

<https://childrensnational.org/departments/center-for-neuroscience-and-behavioral-medicine/programs-and-services/early-childhood-behavioral-health-program/caregiver-webinar>

Overview



ECHO Autism: “All teach. All learn.”

Learning collaboratives between autism specialists and:

1. Allied medical and mental health specialists providing diagnostic and treatment services to children with ASD
2. Primary Care Physicians (e.g., MD, NP, PA)
3. Early Child Care Providers and Educators



Integrated mental health clinicians could attend #1



ECHO Overview



- Free CME
- Team support
- Help with triage & recommendations
- Strong physician satisfaction (94%) & confidence with ability to address ASD

ECHO Autism Primary Care Providers Clinic

Date: Friday, May 27, 2022
Time: 12:00 – 1:00 PM
Session: #10/12
Zoom Connection: <https://echo.zoom.us/j/97211122071>
Call-in number: +1 301 715 8592 US (Washington DC)

This Week's Clinic Didactic

Psychotropic Medications in ASD

Case Presentation

7-year-old male with ASD and questions around gender identity, suicidal comments, diet, and sleep

Presented By:

Kelly Register-Brown, MD

Presented By:

Amy LaCava, MSN, APRN, CPNP-PC, PMHS

Continuing Education Credits

- To claim Medical CME Credits, see the form attached to your calendar invite.
- To claim Psychology and ASHA CEU Credits, please fill out the form which will be posted in the chat toward the end of our ECHO session each week.



JAMA Pediatrics

[View Article ▶](#)

JAMA Pediatr. 2020 May; 174(5): e196306.

Published online 2020 Mar 9. doi: 10.1001/jamapediatrics.2019.6306: 10.1001/jamapediatrics.2019.6306

PMCID: PMC7063545

PMID: [32150229](#)

Effectiveness of the Extension for Community Health Outcomes Model as Applied to Primary Care for Autism

A Partial Stepped-Wedge Randomized Clinical Trial

[Micah O. Mazurek](#), PhD,¹ [Robert A. Parker](#), ScD,^{2,3} [James Chan](#), MA,² [Karen Kuhlthau](#), PhD,^{4,5} and [Kristin Sohl](#), MD⁶, for the ECHO Autism Collaborative

ECHO Sample Didactics

- ASD 101
- ASD Screening
- Supporting a Family While They Wait
- ASD Evaluation 101
- How to talk to families about ASD
- Support Medical Visits
- Identification and Management of Comorbid Medical Problems
- ASD Treatment Planning Overview
- Psychotropic Medication
- Systems Navigation
- Alternative Medication Approaches
- Supporting Transition to Adult Healthcare



ECHO Next Steps

Next Clinics:

- Diagnostic Clinic: July-December 2022
- Educators Clinic: January-June 2023
- PCP Clinic: January-June 2023 (anticipated)



PCPs are welcome to join diagnostic clinics

ECHO Sign Up Contact:

aarmour@childrensnational.org

Future Directions:

- PCP STAT Clinic



STAT: Another PCP or integrated clinician tool to facilitate screening & diagnosis

Screening Tool for Autism in Toddlers & Young Children (STAT™)

Vanderbilt Kennedy Center Online Training

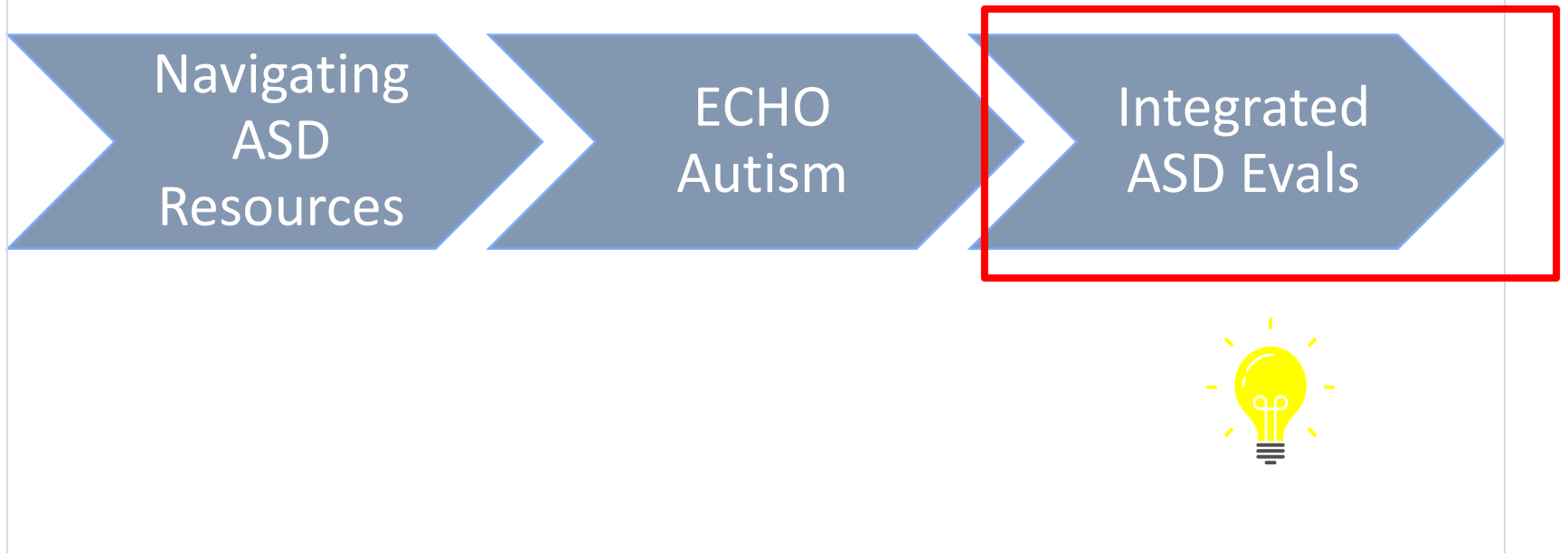
- empirically derived, interactive measure to screen for autism in children 24 - 36 months
- high concurrent validity with the ADOS-2
- 12 items, **~20 minutes** to administer.
- STAT Kit + Additional Provider Certifications = ~\$700.00



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

(~2-4 hours training)

Overview



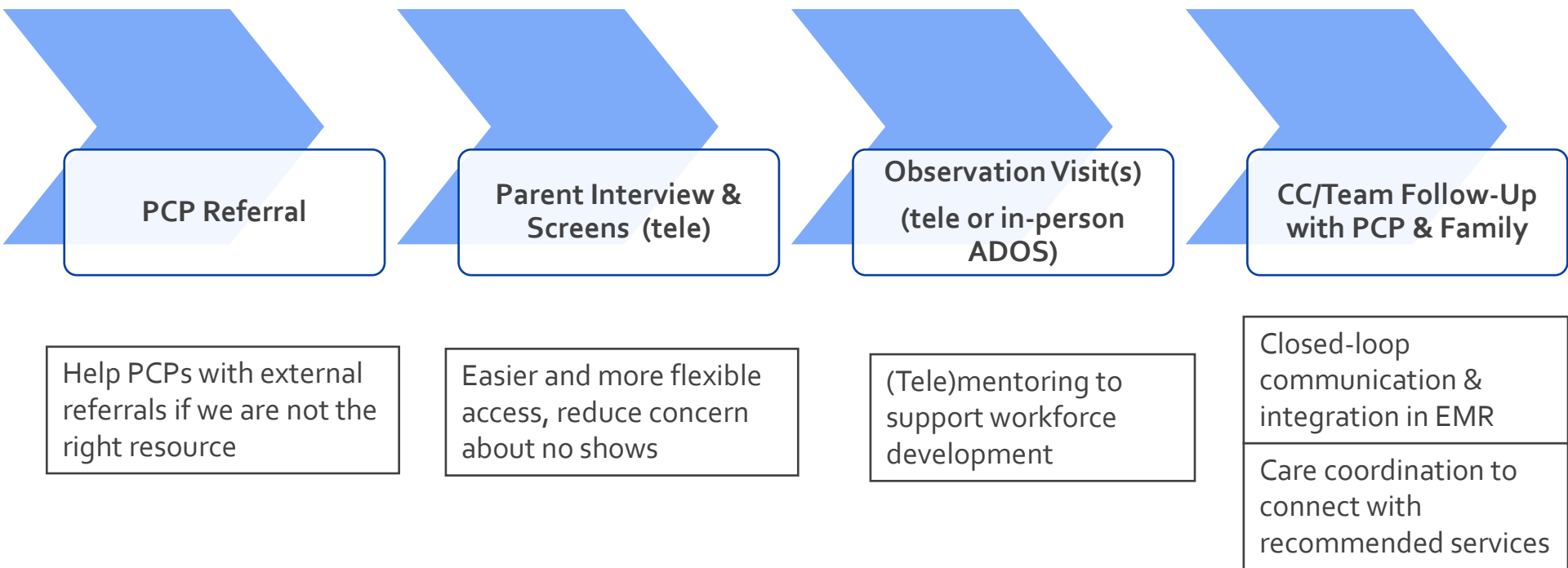
Program Goals

- Timely, equitable ASD evaluations within primary care
- Reduce barriers to care for families
- Increase closed-loop communication with PCPs
- Promote rational use of scarce resources: (Tele)mentoring with ASD experts supporting psychologists working in primary care

Program Overview

- Partnership: Child Health Advocacy Institute, Goldberg, Whole Bear Care, Center for Autism Spectrum Disorders, Psychology
- Currently in 3 Goldberg clinic sites
- Target young children (<5 yrs) with high likelihood of ASD

ASD Primary Care Program Overview



Program Summary:

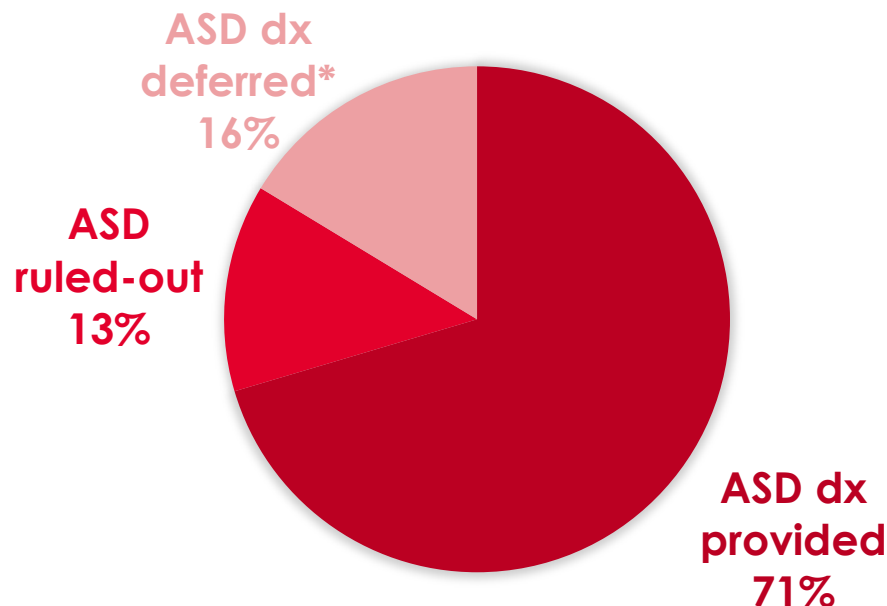
Wait times

- <3 months to complete eval

Child/Family Info

- 34.0 months (SD: 13.81)
- 63% male
- 82% Black/African, 9% Latinx
- 19% not primary English

High PCP & parent
satisfaction (>4/5 ratings)



“This pilot is among the most innovative and impactful primary care pilots I have participated [in]. The leaders of this program are directly serving families who are most likely to be left out of traditional disjointed systems. This program is important to minimize health disparities for historically marginalized groups (Black, low-income) and achieve health equity for children.”- PCP

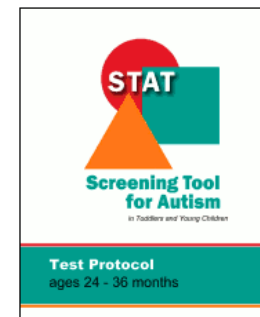
(BACK TO THE) **FUTURE OF PEDIATRICS**

**N=99; Deferred more cases during early COVID due to lack of in person observations*

Lessons Learned



- Some families less prepared for dx of ASD
- Ensuring referrals appropriate for clinic
- Handling multiple no shows during testing blocks
- Learning insurance authorization procedures
- Care coordination needed (though not billable)
 - Average CC duration: 9.4 months
- Adding in multi-step screening or briefer tools



NEXT STEPS: If you have....



5 minutes

- Sign up for ECHO Autism updates



15 minutes

- Download/bookmark ASD e-resources
- Share feedback about the system



1 hour+

- Attend an ECHO clinic
- Learn more about the STAT
- Reach out to us to discuss how ASD evaluations could be integrated into your clinic

Q&A

Questions?

Barriers & facilitators of navigating the system?

Please share feedback

Share Your Feedback and Experiences

This survey is intended to improve children's developmental and behavioral health services within the District by providing feedback on current strengths/challenges to the Child Health Advocacy Institute, the DC Collaborative for Mental Health in Pediatric Primary Care, and other key stakeholders.

Feedback on Developmental and Behavioral Health Services in DC



This survey is intended to improve children's developmental and behavioral health services within the District by providing feedback on current strengths/challenges to the Child Health Advocacy Institute, the DC Collaborative for Mental Health in Pediatric Primary Care, and other key stakeholders.

<https://cri-datacap.org/surveys/?s=3YWLJFLDAA>

Thank You!

Contact Us

Leandra Godoy, PhD

lgodoy@cnmc.org

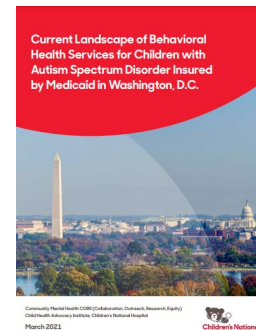
Amanda Hastings, PsyD, BCBA

ahasting@cnmc.org

Melissa Long, MD

mflong@cnmc.org

Additional Resources



<https://childrensnational.org/advocacy-and-outreach/child-health-advocacy-institute/community-mental-health>