

Autism Spectrum Center



Boston Children's Hospital
Autism Spectrum Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

ASD at BCH: 2021



**Boston
Children's
Hospital**

Until every child is well™

**Autism Spectrum
Center**

*Integrated and complementary clinical and
research programs across multiple departments*



**Boston Children's Hospital
Autism Spectrum Center**



**HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL**

ASD at BCH: 2010



Separate and siloed clinical and research programs across multiple departments



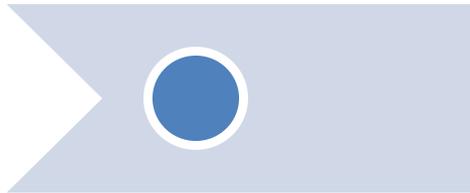
Boston Children's Hospital
Autism Spectrum Center



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The beginning

2011:
“fix this”



20

(



2014: presented to
hospital leadership
Hired Coordination
Intake Team –
gained single point
of access



Boston Children's Hospital
Autism Spectrum Center



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Organization

ASC
Executive
Committee

Co-Directors: Sarah Spence (Neuro) & Carol Weitzman (DDM)

Associate Director: Nancy Sullivan

Program Manager: Alix Morrison

Sarah Spence & Carol Weitzman, MD (Co-Chairs), Sonia Ballal (GI), Stephanie Brewster (TNC), Oscar Bukstein (Psychiatry), Annette Correia (OT), Stephanie Coury, (Genetics), Doug Crook (BRT), Michael Gillespie (VP), Nathan Keegan (Neuro), Patricia Pratt (Nursing), Mustafa Sahin (TNC), Howard Shane (CCE), Donald Surette (DDM)

Child Life
Specialists

Social
Work:

Patient
Family
Educator

Behavior
Analyst

QI
Consultant

Intake
Staff

Kristin
Coffey &
Theresa
McCarthy

Matthew
Snell &
Courtney
Chapman

Katie
Broughey

Olivia
Miller

Madeline
Chiujdea

Niamh
Ryan &
Katie Choi



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Autism Spectrum Center



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ASC Committees

Training

Chairs: Laura Weissman, Kristin Coffey, Dennis Doherty

Provide training to staff and professionals in and outside of BCH

Clinical Care

Chairs: Carol Weitzman, Sarah Spence, Olivia Miller, Matt Snell

Clinical protocols for the ASC

Communications

Chairs: Peter Davis, Katie Broughey, Matt Snell

Disseminate materials to appropriate stakeholders

QI

Chairs, Eugenia Chan, Madeline Chuijdea

Ensure programs and protocols monitored and evaluated

Research

Chairs: Carol Wilkinson, April Levin

Partner with the TNC to ensure high quality ASD research

Parent Advisory

Chairs: Rachel Schmitt, Matt Snell, ?Parent

Engage parents & families in all aspects of the ASC work





Autism Spectrum Center (ASC) Assessment Guideline

Care Standardization

Required for all
diagnostic clinicians

Introduction

The Autism Spectrum Center (ASC) is a multidisciplinary effort at Boston Children's Hospital integrating the expertise of Neurology, Developmental Medicine, Psychiatry, Genetics and Center for Communication Enhancement.

A key goal for the ASC is to standardize care for patients with ASD at Boston Children's Hospital:

- We have developed clinical practice guidelines for the assessment and management of ASD.
- This NetLearning module reviews the key information in the Assessment guideline and addresses standardized practice for diagnosis of ASD.
- Completion of the NetLearning module is **required** to determine eligibility for a clinician to provide diagnostic services for ASD at Boston Children's Hospital.

ASC Executive Committee

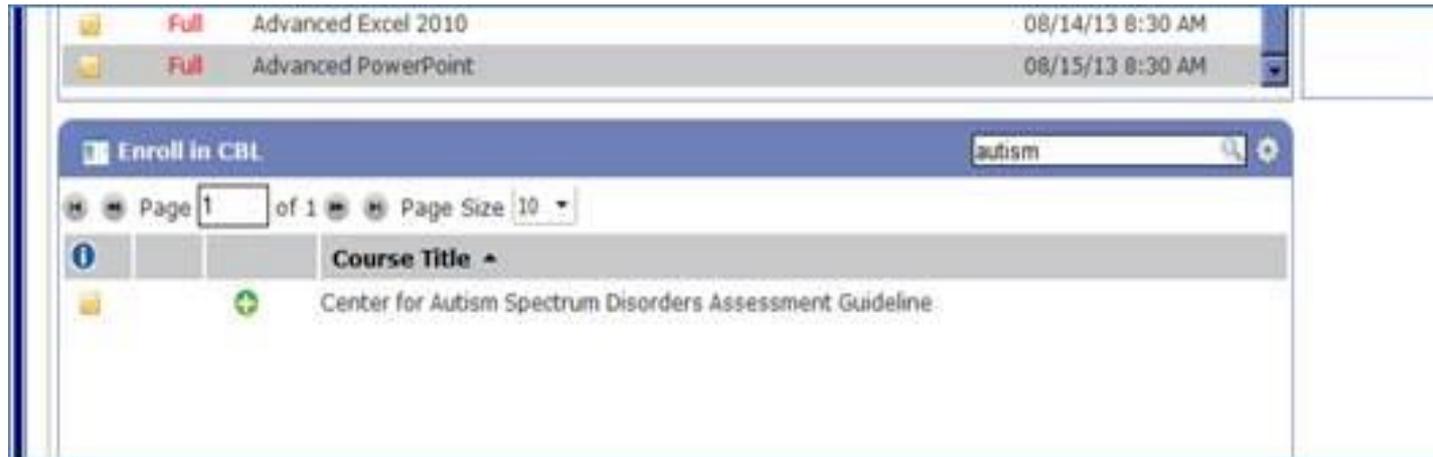
Sarah Spence, MD PhD - Co-Chair

Carolyn Bridgemohan MD - Co-Chair

Eugene D'Angelo PhD

David Miller MD PhD

Howard Shane PhD



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Accurate diagnosis requires history *and* direct observation of child

- History of general development, medical history, review of medical red flags such as regression, seizures or spells
- Review ASD symptoms with developmental focus
- Direct observation of communication, play and behavior
- Data considered in conjunction with DSM 5 criteria

Clinical Practice Guideline for Assessment of ASD



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Autism Spectrum Center



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Accurate diagnosis requires *multidisciplinary* input

- Complete, review results of, or request standardized assessment of
 - Cognitive, language and adaptive skills
 - Social communication skills
(e.g. CARS, STAT, ADOS-2, play assessment)

Clinical Practice Guideline for Assessment of ASD



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Autism Spectrum Center

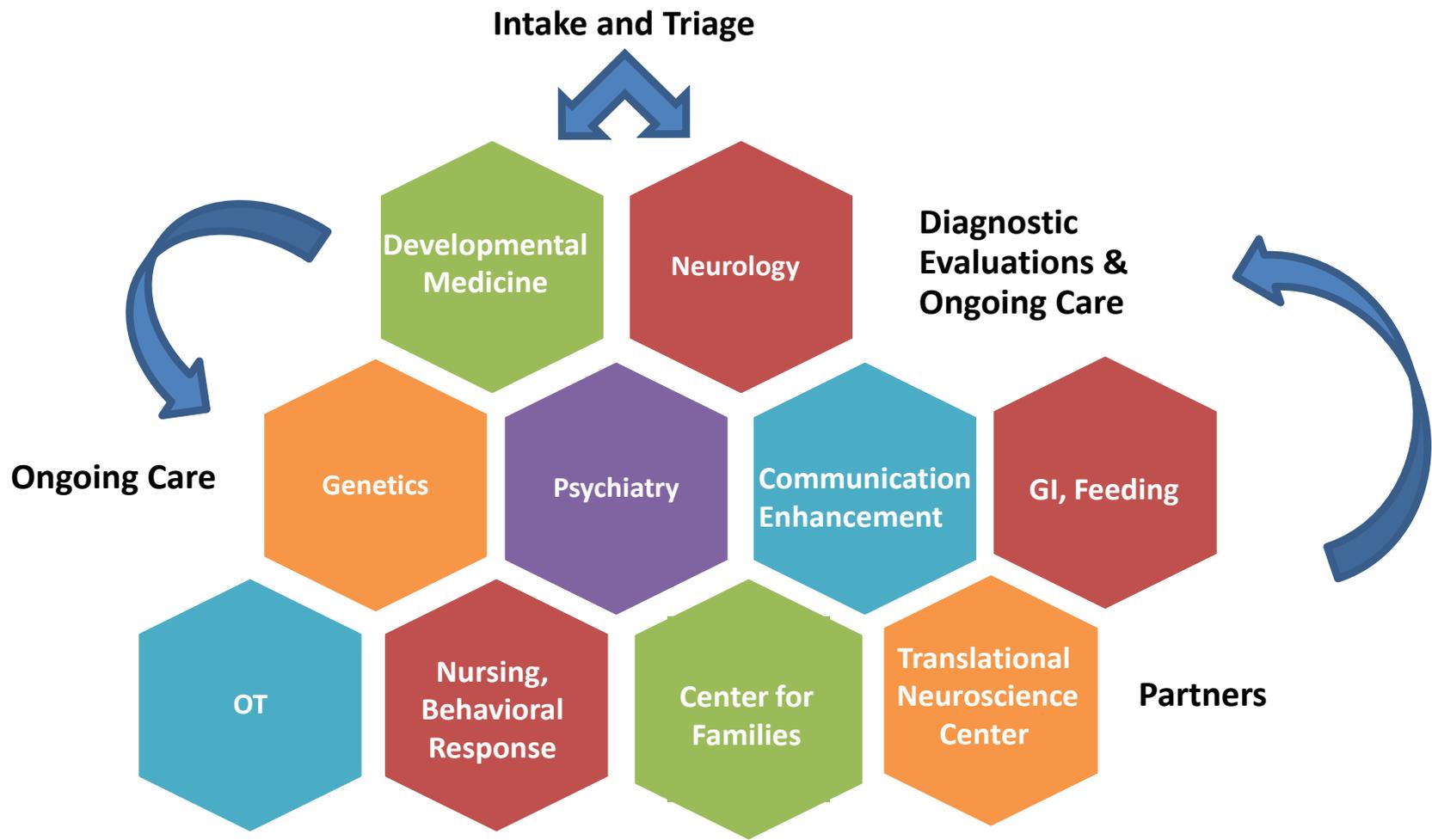


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Importance of Medical Model

- Etiology
- Comorbid conditions
- Medical evaluation and testing
- Family centered care
- Ongoing medical care

Enterprise-Wide Participation



NEW DIAGNOSIS

- That day
 - Family Information Packet “the Blue Folder”(in English and Spanish)
- In the first few months
 - Email newsletters (in English and Spanish)
 - Resources for community/school services
 - Lists and information sheets for ABA, speech/OT/PT, counseling, outside psych/neuropsych testing agencies
 - Both DMC and neurology have resource specialists plus one in the ASC for those not seen in DMC or neuro
 - Autism 101 class
 - New program offered periodically for newly diagnosed families to go over the recommendations in more detail
 - Support groups
 - Spanish language in Peabody
 - English and Spanish at Martha Eliot



Ongoing Resources for families:

- **Resource Team** – Social Work, Patient and Family Educators, Outreach and education to families
- **Email News “blasts”** –quarterly emails provide continued updates on timely health information, research and educational opportunities to all families
- **Community Lectures** – evening talks for families and staff; archived on website
- **ASC website** – links to resource information, community lectures, MyHospitalStories, research opportunities

Autism Spectrum Center

Contact the Autism Spectrum Center Program
617-355-7493

International
+1-617-355-5209

Email
autismcenter@childrens.harvard.edu



Request an Appointment



Request A Second Opinion

Overview

Meet Our Team



Our Services

Resources



Research and Innovation



For Clinicians

Ways to Help

Contact Us

Autism Spectrum Center

Quick links

- [A visual guide to your visit: My Hospital Story](#)
- [Autism Community Lecture Series](#) (check back often for upcoming lectures)
- [Participate in ASD research](#)

If you have a child with [autism spectrum disorder \(ASD\)](#), or if you think your child might have ASD, the Autism Spectrum Center at Boston Children's Hospital is here to help. We partner with families:

- to diagnose ASD as early as possible
- to provide the best integrated care for children at every age
- to support the best possible quality of life for children with ASD and their families
- to help children with ASD reach their full potential
- to create new models of coordinated, autism-friendly clinical care and training
- to develop earlier and more accurate diagnostic tools
- to discover the causes of ASD and find new treatments through one of the most active autism research centers in the world.

We provide comprehensive, family-centered diagnostic and care services for children with autism spectrum disorder, together with [strong family support](#). Depending on your child's needs, we can coordinate visits with [autism specialists](#) such as developmental behavioral pediatricians, child neurologists, psychologists, psychiatrists, geneticists and gastroenterologists, as well as physical, occupational, and speech and language therapists. If you already have a health care provider you like, we can provide any medical services you need to fill in the gaps.

Our ASD services include diagnosis, ongoing management, help with communication and activities of daily life, medication management and specialty care as needed. [Read more about our ASD services.](#)

Families and providers can get information and access all our services through our one-stop phone line: 617-355-7493. Appointments are available at the main hospital in Boston or at our Lexington, Peabody, Waltham and Weymouth [locations](#).

What sets Boston Children's Hospital apart?

Read more about what the Autism Spectrum Center has to offer.



Making visits better

- My Hospital Stories
 - Social Stories
- Behavior support plans (Precautions B)
- New inpatient initiative
- Outcome measure (ASD-PROM)
- Autism Friendly Seal of Approval





Boston Children's Hospital
My Hospital Story
Autism Spectrum Center

- Stories and photographs prepare patients & families for visits & procedures
- Collaborating with Child Life to develop multiple new stories, available on website



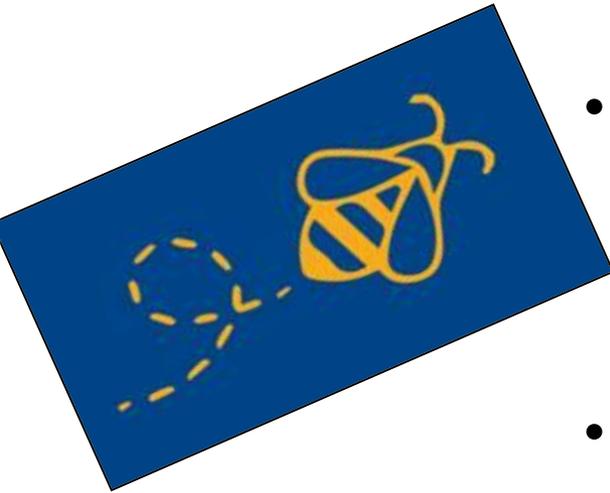
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Behavior Support Plan

= “Precautions B”



- Customized coping/care plan
 - Notes accommodations & interventions that can help, describes communication style, identifies triggers and notes behaviors when in distress including safety concerns
- Promotes safe and successful hospital visits by being ***proactive not reactive***
- Flagged via banner bar in power chart
- Bumble bee door sign for inpatient admissions
- For outpatient staff knows when coming to clinic and can prepare

IMPORTANT TO USE THE “BEHAVIOR SUPPORT PLAN” LANGUAGE WHEN SPEAKING WITH PARENTS. “PRECAUTIONS” CAN SCARE THEM OFF



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Behavior Plan

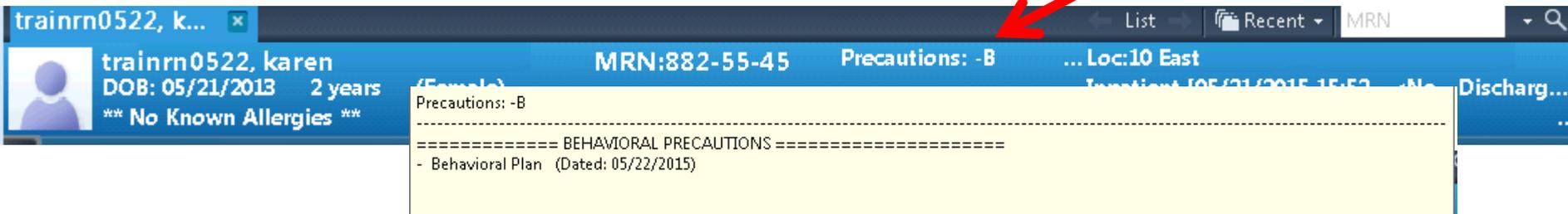
Accommodations	<p>Things that might minimize or prevent child's distress</p> <table border="0"><tr><td><input type="checkbox"/> Avoid rushing, allow time for processing</td><td><input type="checkbox"/> Plan to minimize wait time</td></tr><tr><td><input type="checkbox"/> Allow child to have access to materials/instruments</td><td><input type="checkbox"/> Social stories (prepare your child for the visit/procedure)</td></tr><tr><td><input type="checkbox"/> Distraction tools (toys, puzzles, sensory toys)</td><td><input type="checkbox"/> Talk about procedures/plan in advance</td></tr><tr><td><input type="checkbox"/> Do not have medical discussions in front of patient</td><td><input type="checkbox"/> Transition directly into exam room or low-stimulation area</td></tr><tr><td><input type="checkbox"/> Medication</td><td><input type="checkbox"/> Use of visual schedules or models</td></tr><tr><td><input type="checkbox"/> Minimize number of people in the room</td><td><input type="checkbox"/> Other:</td></tr><tr><td><input type="checkbox"/> Plan for additional people to manage agitation</td><td></td></tr></table>	<input type="checkbox"/> Avoid rushing, allow time for processing	<input type="checkbox"/> Plan to minimize wait time	<input type="checkbox"/> Allow child to have access to materials/instruments	<input type="checkbox"/> Social stories (prepare your child for the visit/procedure)	<input type="checkbox"/> Distraction tools (toys, puzzles, sensory toys)	<input type="checkbox"/> Talk about procedures/plan in advance	<input type="checkbox"/> Do not have medical discussions in front of patient	<input type="checkbox"/> Transition directly into exam room or low-stimulation area	<input type="checkbox"/> Medication	<input type="checkbox"/> Use of visual schedules or models	<input type="checkbox"/> Minimize number of people in the room	<input type="checkbox"/> Other:	<input type="checkbox"/> Plan for additional people to manage agitation	
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Accommodation Details	<p>Please provide additional information or specific details</p> <div style="border: 1px solid black; height: 80px;"></div>														
Interventions	<p>Things that have been helpful when your child becomes agitated or upset</p> <table border="0"><tr><td><input type="checkbox"/> Distraction</td><td><input type="checkbox"/> Parent leaving area (support from staff)</td></tr><tr><td><input type="checkbox"/> Ignoring or offering space</td><td><input type="checkbox"/> Sensory interventions (lights, sound machine, tactile items)</td></tr><tr><td><input type="checkbox"/> iPad/tablet</td><td><input type="checkbox"/> Support from parent</td></tr><tr><td><input type="checkbox"/> Medication</td><td><input type="checkbox"/> Walking</td></tr><tr><td><input type="checkbox"/> Movies/hand held games</td><td><input type="checkbox"/> Weighted blankets/pads</td></tr><tr><td><input type="checkbox"/> Music</td><td><input type="checkbox"/> Other:</td></tr></table>	<input type="checkbox"/> Distraction	<input type="checkbox"/> Parent leaving area (support from staff)	<input type="checkbox"/> Ignoring or offering space	<input type="checkbox"/> Sensory interventions (lights, sound machine, tactile items)	<input type="checkbox"/> iPad/tablet	<input type="checkbox"/> Support from parent	<input type="checkbox"/> Medication	<input type="checkbox"/> Walking	<input type="checkbox"/> Movies/hand held games	<input type="checkbox"/> Weighted blankets/pads	<input type="checkbox"/> Music	<input type="checkbox"/> Other:		
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Communication	<p>Ways your child communicates/understands language</p> <table border="0"><tr><td><input type="checkbox"/> Uses speech</td><td><input type="checkbox"/> Understands manual signs</td></tr><tr><td><input type="checkbox"/> Uses sign language</td><td><input type="checkbox"/> Understands 1-step directions</td></tr><tr><td><input type="checkbox"/> Uses a picture system</td><td><input type="checkbox"/> Understands 2-step directions</td></tr><tr><td><input type="checkbox"/> Uses an electronic communication device</td><td><input type="checkbox"/> Other:</td></tr><tr><td><input type="checkbox"/> Understands visuals</td><td></td></tr></table>	<input type="checkbox"/> Uses speech	<input type="checkbox"/> Understands manual signs	<input type="checkbox"/> Uses sign language	<input type="checkbox"/> Understands 1-step directions	<input type="checkbox"/> Uses a picture system	<input type="checkbox"/> Understands 2-step directions	<input type="checkbox"/> Uses an electronic communication device	<input type="checkbox"/> Other:	<input type="checkbox"/> Understands visuals					
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Behavioral Precautions

- Visible in PowerChart for clinical staff
- Visible in EPIC for front desk staff
- Linked to a behavioral plan identifying triggers, interventions and special accommodations

View a Patient's Behavioral Precautions



The screenshot shows a patient record for 'trainrn0522, karen' with MRN:882-55-45. The 'Precautions: -B' field is highlighted with a red arrow. A pop-up window displays the following text:

```
Precautions: -B
===== BEHAVIORAL PRECAUTIONS =====
- Behavioral Plan (Dated: 05/22/2015)
```

BCH Inpatient Initiative

- Inpatient care guideline for children with ASD
- Completion of autism-informed care plan including Precaution B accommodation plan
- Prompts for appropriate consultations (BCBA, Augmentative Communication, OT, Child Life, Psychiatry)
- Prompts for autism-informed discharge planning

SIMPEDS simulation projects

- EEG lead placement practice and desensitization
 - Peter Davis and Kristin Coffey - Pilot project



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The Autism Friendly Seal:



Resources on Intranet (web2)

Autism Spectrum Center Resources

Autism Spectrum Center External Site

Resource Directories and Fact Sheets

COVID-19 Resources

Blue Folder

Autism Community Lecture Series

AAP Patient Education Handouts-ASD

Inpatient Clinical Pathway

Transition/Transfer to Adult Care

Research

Article: Handle With Care

How to Create a Precautions B Plan in PowerChart

Patient Visit Planning Form

Autism-Friendly Seal of Approval

Autism Spectrum Center Resources

COVID-19 Patient & Provider Resources



Click [here](#) for resources to help support your patients with ASD during the COVID-19 emergency.

New Patient Blue Folder



Need to get a Blue Folder to your new patient but you can't just hand it to them right now? Don't let the COVID-19 emergency get in the way! Click [here](#) to get

My Hospital Story



My Hospital Story is a series of visual stories to help prepare a patient for a hospital visit.

[+ View more](#)



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BCH Staff Education Program

- Providing subject matter expertise to targeted departments via customized training with case discussion
- Case based presentations
- BCBA doing lunch and learns with inpatient staff
- Collaboration with SIMPeds program
 - Simulations for providers (multidisciplinary) with an actor who plays an adolescent with ASD
- Collaboration with OPEN PEDIATRICS
 - To go beyond BCH and reach others at outside institutions



Questions?



Boston Children's Hospital
Autism Spectrum Center



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Children's National.

Autism Diagnostic Integration in Pediatric Primary Care

Serene Habayeb, PhD

Licensed Clinical Psychologist, Department of Psychology and Behavioral Health
Center for Autism Spectrum Disorder
Affiliate Faculty, Child Health Advocacy Institute
Children's National Hospital

Assistant Professor, Depts. of Psychiatry and Behavioral Sciences & Pediatrics
George Washington University Medical School

Program Overview

Identified Problem:

- Long waitlists
- Insurance barriers
- Transportation barriers

Proposed Solution:

- Developed a clinical infrastructure to train embedded psychologists, under mentorship of a psychologist specializing in ASD, to evaluate children deemed at high risk for ASD within their primary care medical home and provide care coordination services.

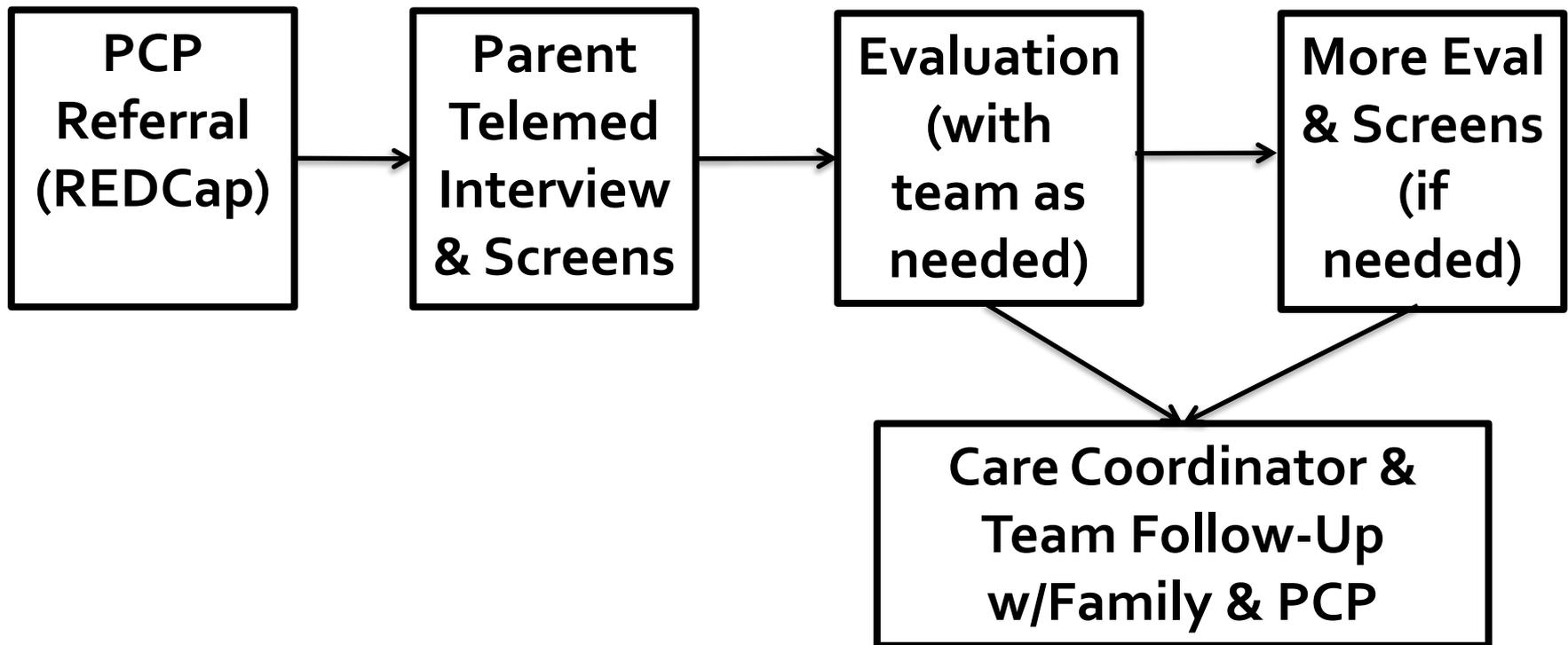


Setting

- Diana L. and Stephen A. Goldberg Center for Community Pediatric Health
 - Largest provider of primary care services in Washington, DC
 - More than 40,000 patients ages birth to 21 (110,000 annual visits)
 - 80% of patients are enrolled in Medicaid
 - 83% are members of ethnic/racial minority groups
- Partnership between:
 - Whole Bear Care (Primary Care Behavioral Health Consultation)
 - DC Mental Health Access in Pediatrics (PCP consultation and community referrals)
 - Center for Autism Spectrum Disorders (CASD)
 - Department of Psychology
 - Child Health Advocacy Center (CHAI) - Community Mental Health CORE

Process Overview

- Started Oct 2019—in person (ADOS) & online (Tele-ASD-PEDS)
- Mixed funding with goal of sustainability
- Recently expanded to additional primary care sites



Who we see

Young children with high likelihood of ASD

<5 years OR with verbal ability below that of a 4-yr-old (not primarily speaking in sentences)

Patients with any insurance and regardless of language preferences

Families appear motivated to complete the assessment

Data Summary (N=60)

Age	M = 33.78 months (SD = 14.41)
Diagnosis	
ASD	67%
Diagnosis ruled out	16%
Diagnosis Deferred	16%
Gender	
Boys	60%
Girls	40%
Language	
English	66%
Other	32%
Insurance	
Medicaid	86%
Private	14%



PCP Perspectives

“This clinic is a HUGE asset. Patients who could not previously get a diagnosis due to barriers in access now are evaluated and diagnosed, and thus have much faster access to services, such as ABA therapy.”

“This has been the best program for our patients. I cannot express enough how helpful this group is in terms of providing a timely diagnosis and connecting families with services. They empower me with detailed information about what my patient needs so that I can help the family even if their team is not immediately available.”

Lessons Learned

- Families are not as ready to learn about their child's diagnosis
- Psychosocial factors add to diagnostic complexities
- Population much more culturally diverse
- Case management supports are invaluable but highlight barriers families face in accessing care

Next Steps

- Ensuring billing sustainability/finalizing pre-authorization procedures
- Training Spanish speaking providers to expand program's reach
- Supporting PCPs ongoing education thorough ECHO autism
- Expanding research component

THANK YOU!

QUESTIONS? FEEDBACK?



Annie Inge, PhD



Erica Eisenman, PsyD



Leandra Godoy, PhD



Serene Habayeb, PhD



Amanda Hastings, PsyD, BCBA



Amanda Hastings, PsyD



Sharon Singh, PhD



Renee E. Williams, MSHEP, CHES

Integrating Autism Diagnostic Services with Medical Services

Janice Keener, Psy.D.
Clinical Psychologist
Director of Psychological and Assessment Services
Developmental Pediatrics
Assistant Professor
Eastern Virginia Medical School





Children's Hospital of The King's Daughters



Our Hospital Today

- Virginia's only free-standing, full-service pediatric hospital
- 206 licensed beds
- Located in Norfolk, VA
- Not-for-profit
- 5,000+ admissions a year
- Teaching hospital
- Home of Eastern Virginia Medical School



Department of Pediatrics

- Heart of a comprehensive pediatric healthcare system

Our Service Area

-  **Southeastern Virginia**
-  **Northeastern North Carolina**
-  **Virginia's Eastern Shore**
-  **2 million people**
-  **460,000 children**
-  **11,500 square miles**



Virginia Department of Health Service Contract

VDH has consolidated services from the Child Development Centers (CDC) throughout Virginia into regional centers

The CDC at the Norfolk Department of Health closed in 2013

Contract with CSG started Dec 2013

Provides support for additional staff needs:

Developmental
Pediatricians/Psychology

SW

Administrative staff

Developmental Pediatrics Clinic Composition

2011

- 2.0 FTE Dev Peds
- 0.8 FTE Ed Specialist
- 0.8 FTE SW

2016

- 3.0 FTE Dev Peds
- 2.7 FTE Psychology
- 3.0 FTE Ed Specialist
- 2.0 FTE MSW

2019

- 2.0 FTE Dev Peds
- 3.7 FTE Psychology
- 2.0 FTE Nurse Practitioners
- 3.0 FTE Ed Specialist
- 1.0 FTE MSW
- .5 FTE Autism Care Coordinator

2020

- 1.0 FTE Dev Peds
- 2.7 FTE Psychology
- 3.0 FTE Nurse Practitioners
- 3.0 FTE Ed Specialist
- 1.0 FTE MSW
- .5 FTE Autism Care Coordinator

2021

- 1.25 FTE Dev Peds
- 2.8 FTE Psychology
- 3.0 FTE Nurse Practitioners
- 3.0 FTE Ed Specialist
- 1.0 FTE MSW
- .5 FTE Autism Care Coordinator

Referral Process

Referrals are from general pediatricians or from community agencies

Patients are usually seen first by a Dev Pediatrician (or NP) and then referred for other services including assessment with psychology

MSW phone intake may be required for older or more complex patients, with the goal of providing referrals to community services for those most at need and to determine if the patient is best served in Developmental Pediatrics

Assessment Process

Psychology Assessment

- Review of assessment protocols of Autism centers nation-wide
 - Standardization of assessment protocols to be consistent with other major centers
 - Able to assess child from multiple points (i.e., school, home, in-office)
 - Multiple office visits aides in diagnosis
- ADOS-2/ADI-R/Tele-ASD Peds
- Cognitive
- Adaptive Functioning
- Parent and Teacher Behavior Rating Scales

Educational Specialist

- School liaison

Autism Resource Coordinator

- Family support/Community resources

Referrals

ABA therapy

Parent Resource Group

Autism Resource
Coordinator

School special education
programs

Early Intervention

Counseling Services

Clinic Process Changes Due to Increased Family Stress Levels

**Development of
supportive services to
decrease perceived
social isolation in
caregivers of children
with ASD**



**Families are now
referred to the Family to
Family Network and
Tidewater Autism
Society of America**

QUESTIONS?



Interdisciplinary Autism Evaluations: Bridging Primary Care and Developmental Pediatrics

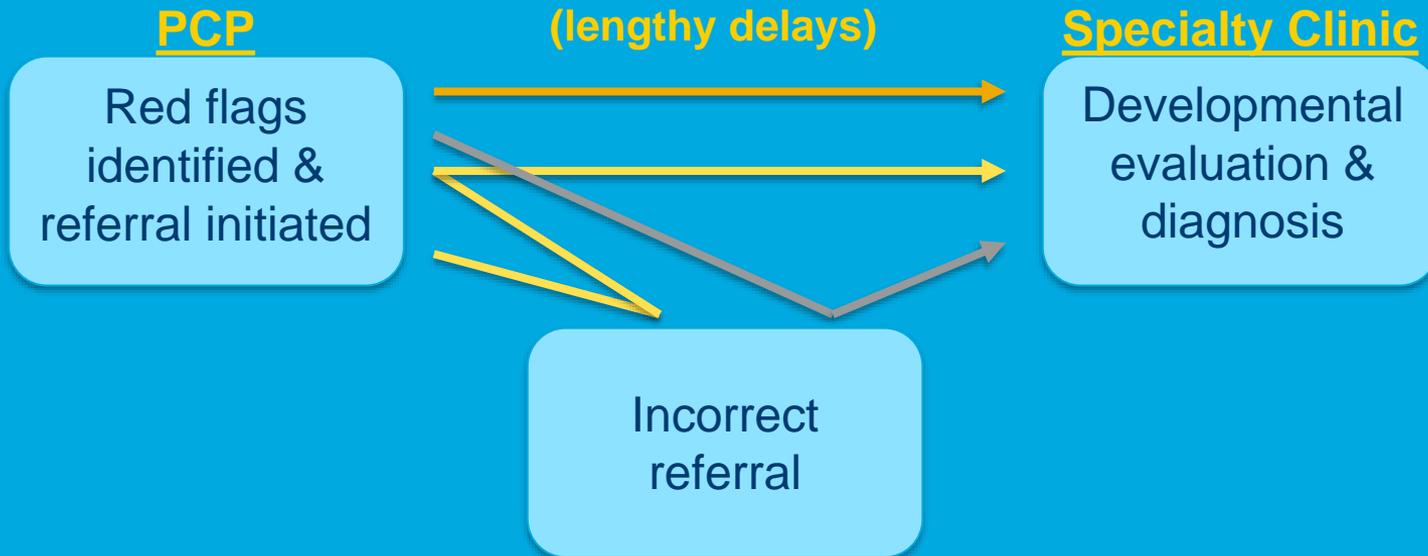
Maritza Cobian, PsyD

AUGUST 25, 2021



Path to partnership

- Early identification of **red flags** and ASD
- Role of primary care settings

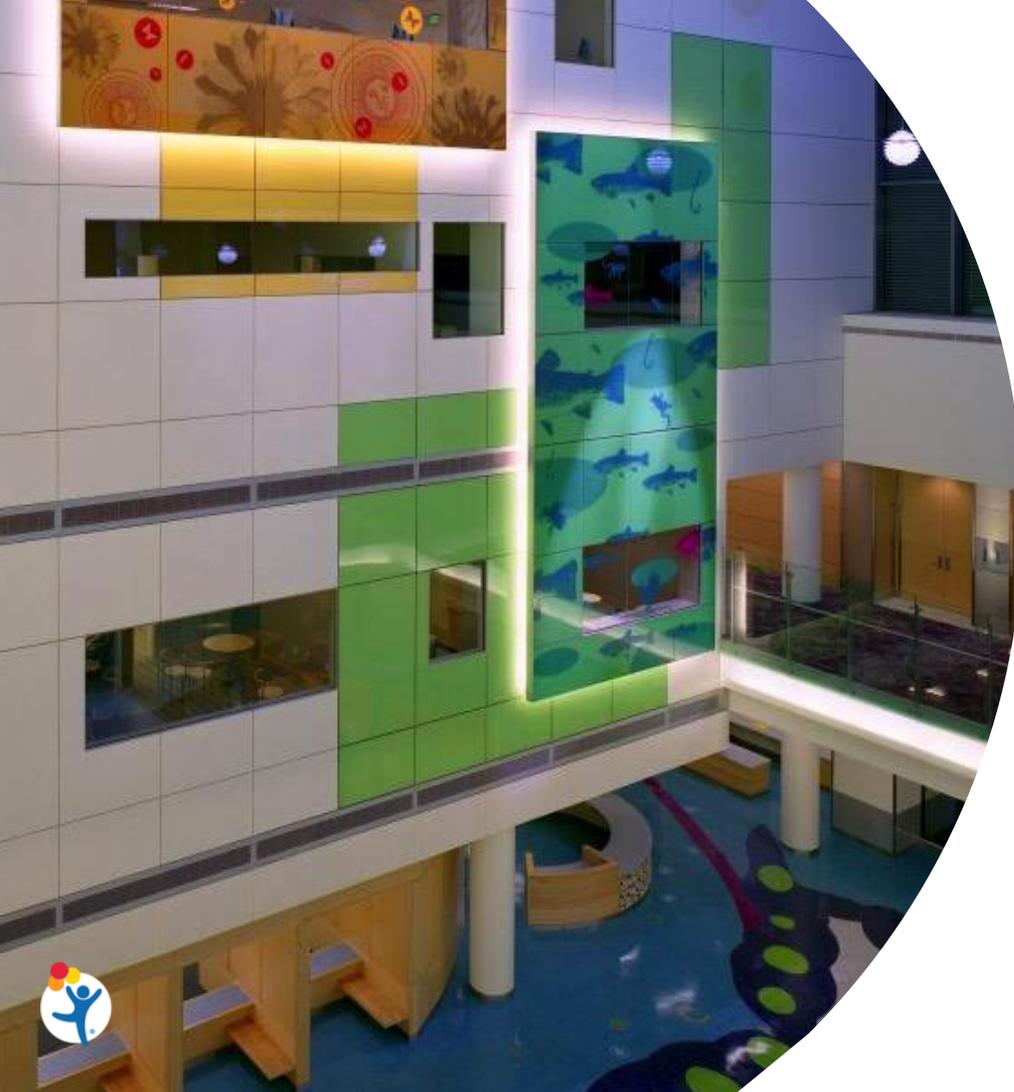




Child Health Clinic (CHC)

- Comprehensive primary care clinic
- Serves children birth to adolescence
- Developmental Behavioral Pediatrician (DBP) provides developmental consultations





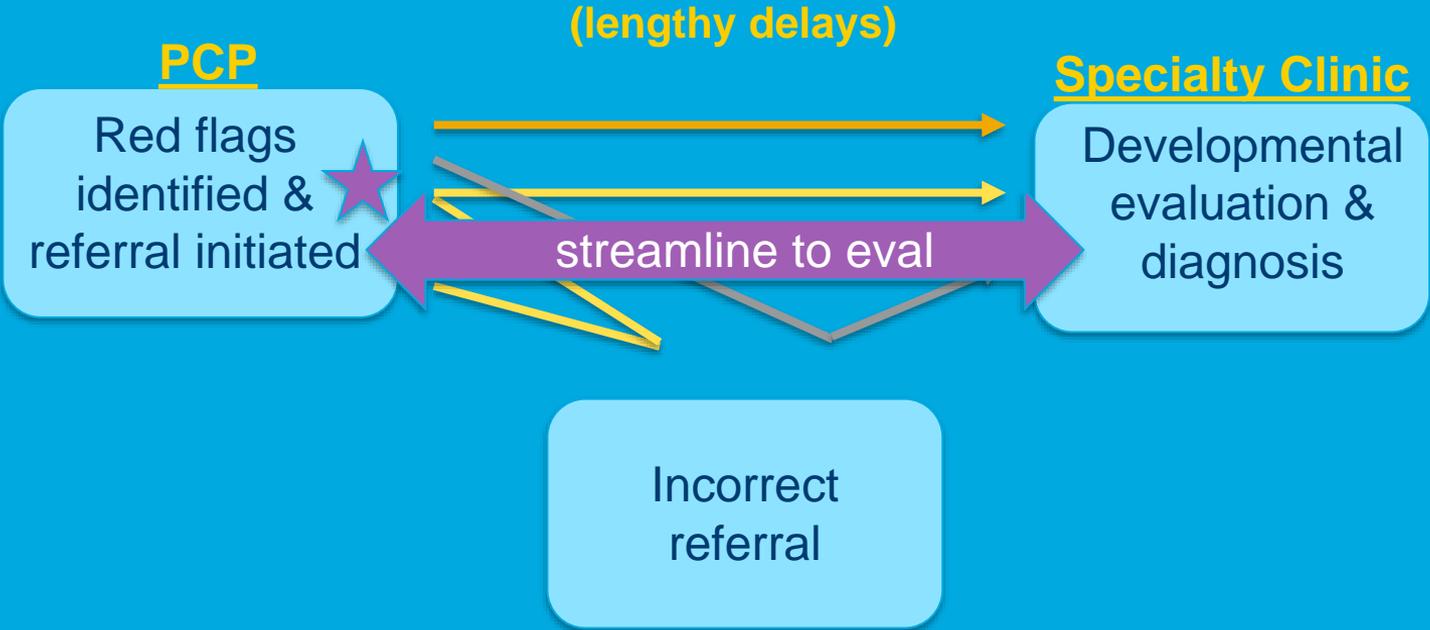
Developmental Team Clinic

Clinic located at CHCO Main Location, near
CHC primary care setting

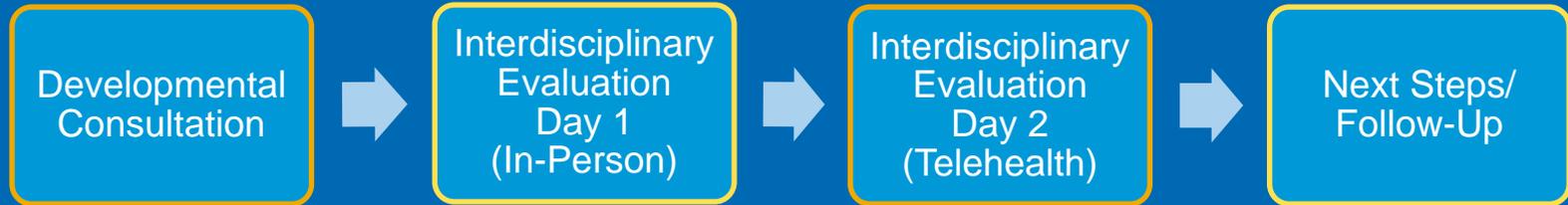
Team:

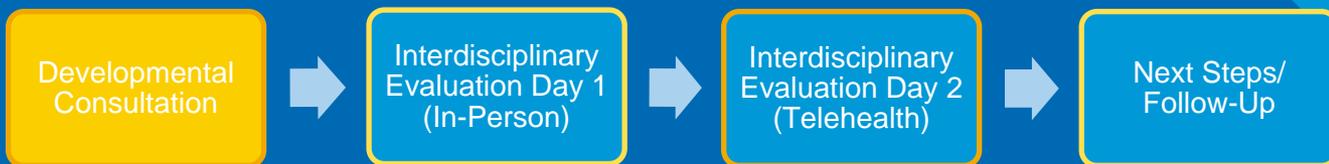
- 1 Developmental Behavioral Pediatrician
- 3 Clinical Psychologists
- Rotating DBP Fellows





Comprehensive Evaluation Timeline





Developmental Consultation

- Follows referral from PCP due to failed MCHAT and history of delayed developmental milestones
- Takes place in primary care setting familiar and accessible to family
- Possible outcomes:
 - ASD diagnosis provided at developmental consultation
 - Further developmental assessment is required





Interdisciplinary Evaluation Day 1

- Initial in-person visit with evaluation team
- DBP: medical and developmental interview, adaptive behavior testing, physical examination
- Psychologist: developmental/cognitive testing, autism-specific testing
- Evaluation team staffs and finalizes diagnoses and recommendations





Interdisciplinary Evaluation Day 1

Testing Battery:

Adaptive Behavior Testing:

- Vineland Adaptive Behavior Scales, 3rd Edition

Developmental Testing:

- Bayley Scales of Infant and Toddler Development, 3rd Edition

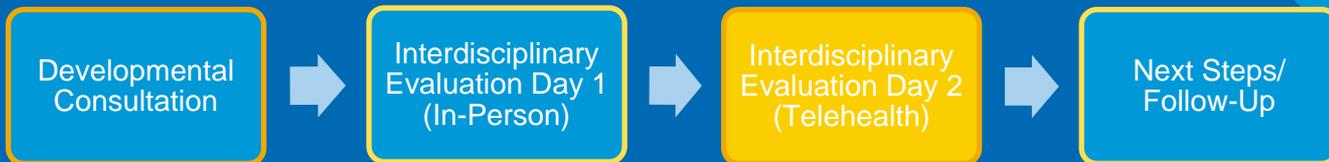
Cognitive Testing:

- Differential Ability Scales, 2nd Edition
- Weschler Intelligence Scale for Children, 5th Edition

Autism-Specific Testing:

- Autism Diagnostic Observation Schedule, 2nd Edition (ADOS-2)

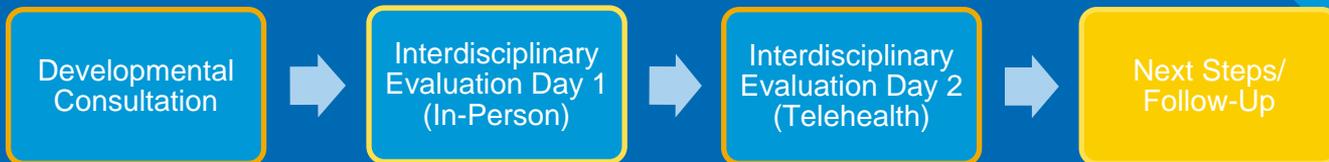




Interdisciplinary Evaluation Day 2

- Telehealth follow-up visit to review testing results, diagnoses, and recommendations
- Psychologist and DBP collaborate to share feedback with family
- Family is provided with After Visit Summary
 - Team Recommendations
 - Medical Recommendations (e.g., therapy referrals, genetic testing, sleep, toileting)





Next Steps/Follow-Up

- Findings shared with referring, primary care provider
 - Continues to follow for primary care needs
 - Family Navigator
- Developmental Pediatrics Social Work Team (Next Steps Clinic)
 - Family referred by evaluation team following feedback visit
 - Assist with insurance, educational, treatment/services needs
- Patient follows-up with DBP in 6-12 months
 - Determine if connection to services has been made
 - Communicate genetic testing findings



Interdisciplinary Documentation

Available at the
Feedback Visit

- After visit summary
- Team recommendations

Available 3-4
weeks following
feedback visit

- Medical report
- Psychology report



Areas To Consider And Grow

- Families not ready for ASD diagnosis at developmental consultation
- Hybrid model is not good fit for all families



Thank You



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