Autism Spectrum Center
ASD at BCH: 2021

Integrated and complementary clinical and research programs across multiple departments
ASD at BCH: 2010

Separate and siloed clinical and research programs across multiple departments
The beginning

2011: “fix this”

2012: created the clinical practice guidelines

2013: granted “center” status, est autism friendly hospital initiative

2014: presented to hospital leadership

Hired Coordination Intake Team – gained single point of access
<table>
<thead>
<tr>
<th>ASC Committees</th>
<th>Training</th>
<th>Clinical Care</th>
<th>Communications</th>
<th>QI</th>
<th>Research</th>
<th>Parent Advisory</th>
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<tr>
<td><strong>Chairs:</strong> Laura Weissman, Kristin Coffey, Dennis Doherty</td>
<td><strong>Chairs:</strong> Carol Weitzman, Sarah Spence, Olivia Miller, Matt Snell</td>
<td>Provide training to staff and professionals in and outside of BCH</td>
<td><strong>Chairs:</strong> Peter Davis, Katie Broughey, Matt Snell</td>
<td><strong>Chairs:</strong> Eugenia Chan, Madeline Chuijdea</td>
<td><strong>Chairs:</strong> Carol Wilkinson, April Levin</td>
<td><strong>Chairs:</strong> Rachel Schmitt, Matt Snell, ?Parent</td>
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<tr>
<td><strong>Clinical protocols for the ASC</strong></td>
<td><strong>Disseminate materials to appropriate stakeholders</strong></td>
<td><strong>Ensure programs and protocols monitored and evaluated</strong></td>
<td><strong>Partner with the TNC to ensure high quality ASD research</strong></td>
<td><strong>Engage parents &amp; families in all aspects of the ASC work</strong></td>
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</table>
Contact our intake team: 617-355-7493
autismcenter@childrens.harvard.edu

Complete intake forms

Triage team review and assignment to next available and most appropriate visit
Autism Spectrum Center (ASC) Assessment Guideline

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 Bridgeman MD - Co-Chair
Eugene D'Angelo PhD
David Miller MD PhD
Howard Shane PhD

Care Standardization Required for all diagnostic clinicians
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
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)
Importance of Medical Model

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

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 disorders, 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: 617-355-7499. 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
• Stories and photographs prepare patients & families for visits & procedures
• Collaborating with Child Life to develop multiple new stories, available on website
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**

*Boston Children’s Hospital Autism Spectrum Center*

*HARVARD MEDICAL SCHOOL TEACHING HOSPITAL*
# Behavior Plan

## Accommodations

**Things that might minimize or prevent child's distress**

- Avoid nothing, allow time for processing
- Allow child to have access to materials/instruments
- Distraction tools (toys, puzzles, sensory toys)
- Do not have medical discussions in front of patient
- Medication:
- Minimize number of people in the room
- Plan for additional people to manage agitation

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<th>Accommodation Details</th>
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<td>Please provide additional information or specific details</td>
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## Interventions

**Things that have been helpful when your child becomes agitated or upset**

- Distraction
- Ignoring or offering space
- Feet/hand in ice
- Meditation
- Movement/hand held puzzles
- Music

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<th>Intervention Details</th>
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<td>Please provide additional information or specific details</td>
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## Communication

**Ways your child communicates/understands language**

- User speech
- User sign language
- User a picture system
- User an electronic communication device
- Understands visuals

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<th>Communication Details</th>
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</table>
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
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
The Autism Friendly Seal:

March 12, 2018

Autism Spectrum Friendly
name of clinic/area

has been awarded Autism Spectrum Friendly status. We are devoted to creating an environment that supports children with Autism Spectrum Disorder (ASD).

Ask us how we can help your family!
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...
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?
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
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)

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<tr>
<td>Private</td>
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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
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

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<tr>
<th>Year</th>
<th>2011</th>
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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
<table>
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<td>ABA therapy</td>
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<tr>
<td>Early Intervention</td>
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<tr>
<td>Counseling Services</td>
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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
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

**PCP**
- Red flags identified & referral initiated

**Specialty Clinic**
- Developmental evaluation & diagnosis

Incorrect referral

(lengthy delays)
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
Red flags identified & referral initiated

PCP

(streamline to eval)

Incorrect referral

Specialty Clinic

Developmental evaluation & diagnosis

(lengthy delays)
Comprehensive Evaluation Timeline

Developmental Consultation → Interdisciplinary Evaluation Day 1 (In-Person) → Interdisciplinary Evaluation Day 2 (Telehealth) → Next Steps/ Follow-Up
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