A Joint Network

The Network is a collaboration between

Autism Intervention Research Network on Physical Health

And

Autism Treatment Network
Autism Spectrum Disorder (ASD) is defined as a group of behaviors indicating social, communicative, and behavioral impairment.

- CDC estimates autism’s prevalence as 1 in 68 children in the United States.
- Ratio of Boys:Girls with autism is around 4:1
Autism and the Native American Community

• In the 2016 CDC *Community Report on Autism*, less than 1% of the children tracked were of American Indian or Alaska Native descent.

• According to the American Speech-Language-Hearing Association’s *Epidemiology Across Cultures: American Indian and Alaska Native Populations* Report:
  → **.18%** of American Indian and Alaska Native students age 6-21 received special education services for autism in 2004

https://www.asha.org/Practice/multicultural/american-indian/
Comorbidities

One third of people with autism remain nonverbal.

One third of people with autism have an intellectual disability.

Medical and mental health issues frequently accompany autism. They include gastrointestinal (GI) disorders, seizures, sleep disturbances, attention deficit and hyperactivity disorder (ADHD), anxiety and phobias.

https://www.autismspeaks.org/what-autism
Autism is described by a range of conditions characterized by:

- Challenges with Social Skills
- Repetitive Behaviors
- Challenges with Social Communication
- Unique Strengths and Differences

https://www.autismspeaks.org/what-autism
Network Mission

To improve the well-being of children with ASD and their families by making a high quality, comprehensive, and multidisciplinary care accessible within local communities.

Key activities:
• Research related to the physical health of children with ASD
• Create and disseminate standards of care
• Spread and implement best practices
• Provide training for families and providers

Core values:
• Equity/Reducing Disparities
• Family co-production and involvement
Who Leads the Network

- Partnerships
  - Clinical Coordinating Center
  - HRSA
  - Autism Speaks

- Network Steering Committee

- Family Advisory Committee

- Key Collaborators
  - Data Coordinating Center
  - Anderson Center

- 12 collaborating Sites
Network Accomplishments To Date

• Served nearly 50,000+ patients with ASD
• Released 23 toolkits with over 350,000 downloads (and counting!)
• 5 practice guidelines
• In 2016, held 1,000+ community events & training sessions throughout US and Canada - reaching 50,000+ professional & community members, mentored over 1,300 investigators and students
• Improvement
  – Insomnia and constipation screening and care plan development
  – Anti-psychotic medication monitoring
  – Improved access at 2 sites
  – Enhanced network capacity to carry out activities using QI methodology
  – Launched Learning Network
Network Objectives

Research

- Mentorship of New Investigators
- Creating Best Practices and Standards of Care
- Quality and Practice Improvement
- Committees and Workgroups

Dissemination
Completed Research

- Sleep
- Nutrition and Wellness
- Daily Living Skills
- Neurology
- GI
- Bones
- Longitudinal Research Registry
Ongoing Research

- ECHO
- Probiotics
- Learning Network
- Longitudinal Research Registry
- DSM-5
- Dental
- Physical Exercise and Anxiety
- Family Navigation
- Drug Trials
With thanks to: Kristin Sohl, MD, FAAP, Alicia Curran, BS, Micah Mazurek, MD, Missouri ECHO Autism Hub, Courtney Burnette, PhD, Jane Oski, MD, ECHO Hub participants, ECHO spoke participants, families.
ECHO Autism Clinic Framework

- Curriculum based on ATN/AIRP guidelines and research discovery
- Flexible agenda to address most current advances in care
- Case-based guided practice for community physicians/providers
- Access to patient and parent education
- 90 minutes, 2 times per month

ECHO Autism Hub Team

- Kristin Sohl, MD
  Director
- Kelly Scheilitz, PhD
  Clinical Psychologist
- Rachel Brown, MD
  Child & Adolescent Psychiatrist
- Sheila Chapman, MS, RDN
  Registered Dietitian
- Alicia Curran, BS
  Parent Expert
- Melinda Odum, LCSW
  Resource Expert
ECHO core framework description
ECHO Platform

HUB Team

Spoke Participants
ECHO Autism Goals

• Increase local access to high quality health care for children with ASD

• Increase PCP self-efficacy with identification of ASD symptoms in children between 12 months and 18 years of age

• Increase PCP self-efficacy in assessing and treating common medical and psychiatric comorbidities in children with autism

• Decrease the wait for a diagnostic evaluation for children 14 to 48 months, with the highest risk factors
ECHO Autism Study Aims

To determine whether participation in ECHO Autism will result in improved:

1. **ASD Knowledge**
2. **Clinical Practice Behavior** in ASD screening/identification and co-morbidity management
3. **Self-efficacy** in ASD screening/identification and co-morbidity management
## ECHO Autism Study: Timeline

<table>
<thead>
<tr>
<th>Cohort 1: Arkansas CHOP</th>
<th>December 1, 2016</th>
<th>March 1, 2017</th>
<th>June 1, 2017</th>
<th>September 1, 2017</th>
<th>December 1, 2017</th>
<th>March 1, 2018</th>
<th>June 1, 2018</th>
<th>September 1, 2018</th>
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<tbody>
<tr>
<td>Cohort 2: Rochester Toronto</td>
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<td>T2: 3 mo Assessments</td>
<td>T3: 6 mo Assessments</td>
<td>T4: Final Assessments</td>
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<td>Cohort 3: Lurie Center Vanderbilt</td>
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<td>T2: 3 mo Assessments</td>
<td>T3: 6 mo Assessments</td>
<td>T4: Final Assessments</td>
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<td>Cohort 4: Pittsburgh UC Irvine</td>
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<td>T2: 3 mo Assessments</td>
<td>T3: 6 mo Assessments</td>
<td>T4: Final Assessments</td>
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<td>Cohort 5: Cincinnati Nationwide</td>
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<td>T2: 3 mo Assessments</td>
<td>T3: 6 mo Assessments</td>
<td>T4: Final Assessments</td>
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**Timeline Details:**
- **C1 Recruitment:** September 1, 2016 – November 31, 2016
- **C2 Recruitment:** December 1, 2016 – February 28, 2017
- **C3 Recruitment:** March 1, 2017 – May 31, 2017
- **C4 Recruitment:** June 1, 2017 – August 31, 2017
- **C5 Recruitment:** September 1, 2017 – November 31, 2017

**Key Dates:**
- **T1:** ECHO Launch
- **T2:** 3 mo Assessments
- **T3:** 6 mo Assessments
- **T4:** Final Assessments
The Missouri Diagnostic Model*

Right Care, Right Time, Right Place

Tier 1
ECHO Autism STAT

Tier 2
ECHO Autism Diagnosis

Tier 3
Tertiary Autism Center

Increased access to timely, high quality diagnosis

*Concept being developed
Figure showing STAT additional elements

STAT Training
2 Days

STAT Reliability
6 months

ECHO Autism
1st and 3rd Wednesday
11:45a-1:15p

Diagnostic Cases
Through ECHO Autism
Save the Date: STAT! Training
Presented by the UNM Center for Development and Disability and ECHO Autism

- **What is STAT?** The Screening Tool for Autism in Toddlers (STAT) is a secondary screener that can help differentiate children who are at highest risk for ASD

- **Who can participate in STAT! Training?** IHS Providers (Peds, Family Medicine, NP, PA)

- **When will the FREE training be held?** January 25th and 26th, 2017

- **Where will the FREE training be held?** Chinle, AZ*

  *Travel costs including a 1 night hotel stay for participants will be covered

- **What are the benefits of participation?**
  - Free CME Hours
  - State-of-the-Art Training in advanced autism screening
  - $300 per participant incentive

For questions, contact: Audrey Wolfe at AWOLFE2@mgh.harvard.edu
To Learn More About and Engage with the Network

Please visit our Websites!

ATN
• www.asatn.org

AIR-P
• www.airpnetwork.org
Questions?