ATN/AIR-P Autism Network

Karen Kuhlthau, PhD

kkuhlthau@mgh.harvard.edu

A Joint Network

The Network is a collaboration between

Autism Intervention Research Network on Physical Health

And

Autism Treatment Network

Autism Spectrum Disorder

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

Center for Disease Control and Prevention

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.cdc.gov/ncbddd/autism/documents/comm-report-autism-full-report.pdf

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

AIR P
Autism Intervention Research
Network on Physical Health

AUTISM SPEAKS
ATN
Autism Treatment Network

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.

Autism is described by a range of conditions characterized by:

Challenges with Social Skills

Repetitive Behaviors

wiki How to Understand Repetitive Behaviors from Blind or Visually Impaired Children

Challenges with Social Communication

Unique Strengths and Differences

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
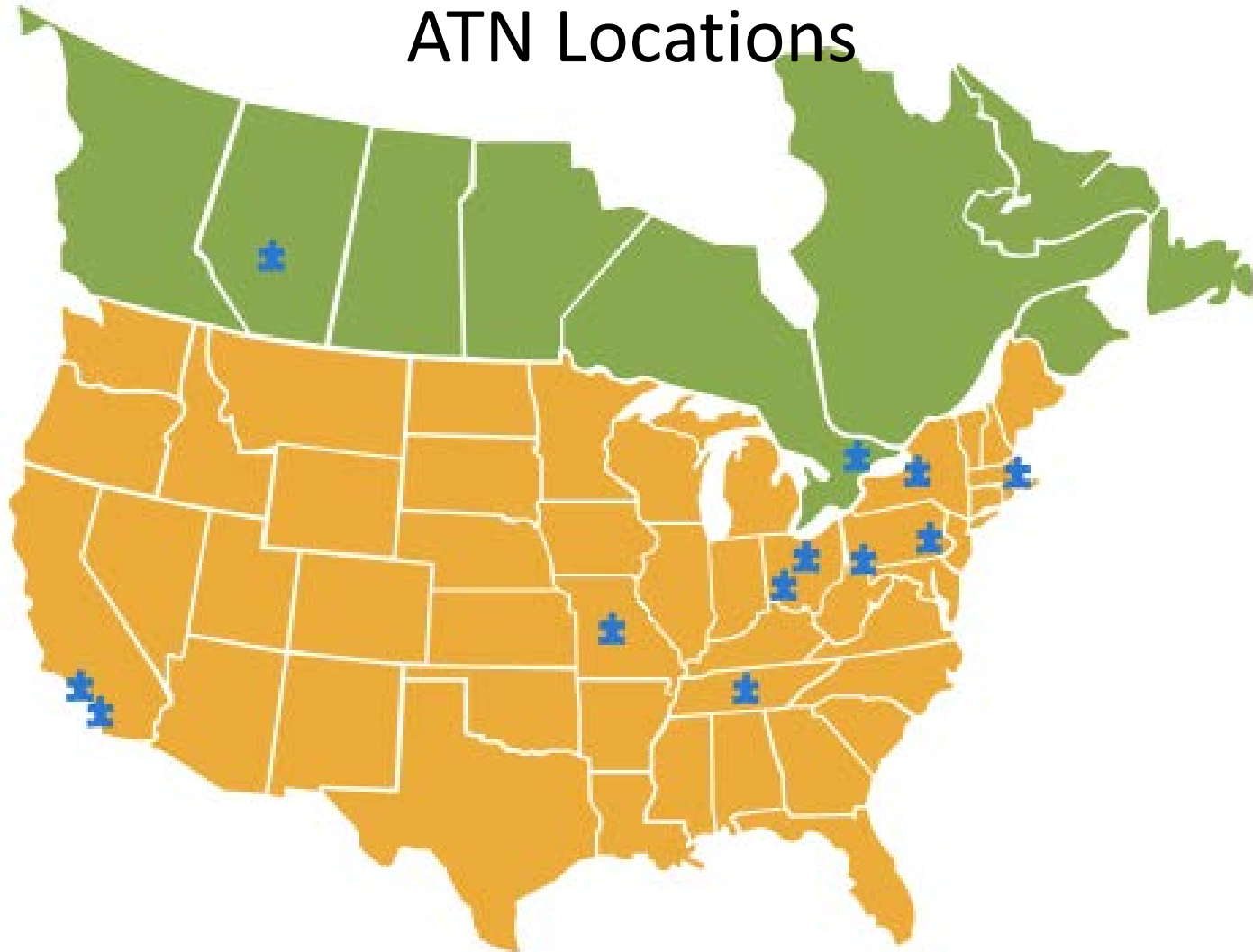- Family co-production and involvement

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

ATN Locations

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

Dissemination

Committees and Workgroups

Completed Research

Neurology

Sleep

Nutrition and Wellness

GI

Bones

Daily Living Skills

Longitudinal Research Registry

Ongoing Res...

ECHO

Probiotics

Learning Network

Longitudinal Research Registry

DSM-5

Dental

Physical Exercise and Anxiety

Family Navigation

Drug Trials

AUTISM SPEAKS

ATN
Autism Treatment Network

AIR
Autism Intervention Research
Network on Physical Health

ECHO Autism

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 Scheiltz, PhD
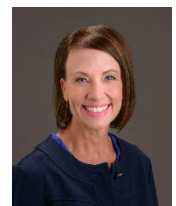**Clinical Psychologist**

Rachel Brown, MD
Child & Adolescent Psychiatrist

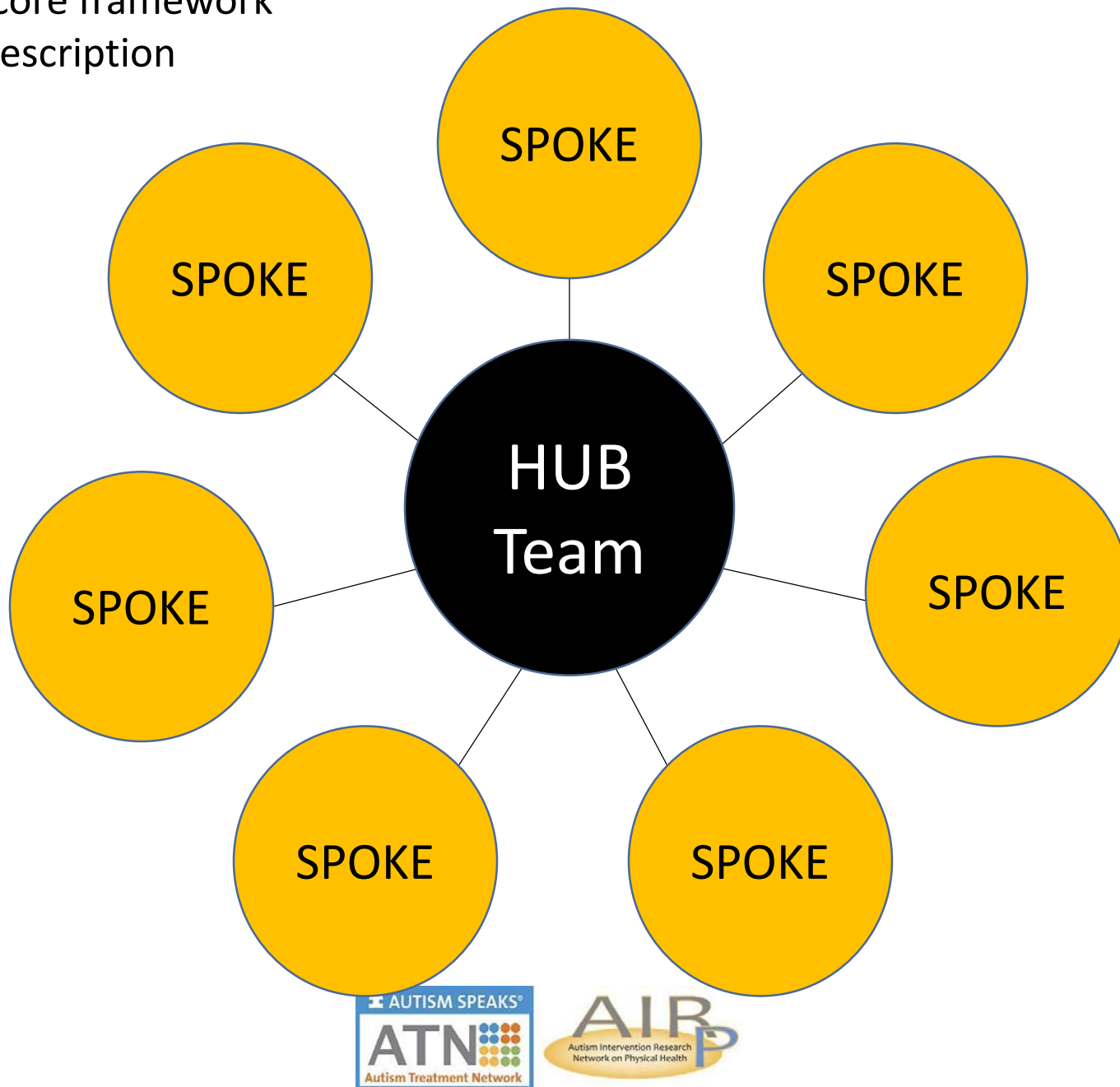**Sheila Chapman, MS, RDN**
Registered Dietitian

Alicia Curran, BS
Parent Expert

Melinda Odum, LCSW
Resource Expert

AUTISM SPEAKS®
ATN
Autism Treatment Network

AIRP
Autism Intervention Research
Network on Physical Health

ECHO core framework description

ECHO Platform

HUB Team

Spoke Participants

ECHO Autism Goals

- Increase <u>local access to high quality health care</u> for children with ASD

- Increase PCP self-efficacy with <u>identification</u> of ASD symptoms in children between 12 months and 18 years of age

- Increase PCP self-efficacy in assessing and treating common <u>medical and psychiatric</u> comorbidities in children with autism

- <u>Decrease the wait</u> for a diagnostic evaluation for children 14 to 48 months, with the highest risk factors

ECHO Autism Study Aims

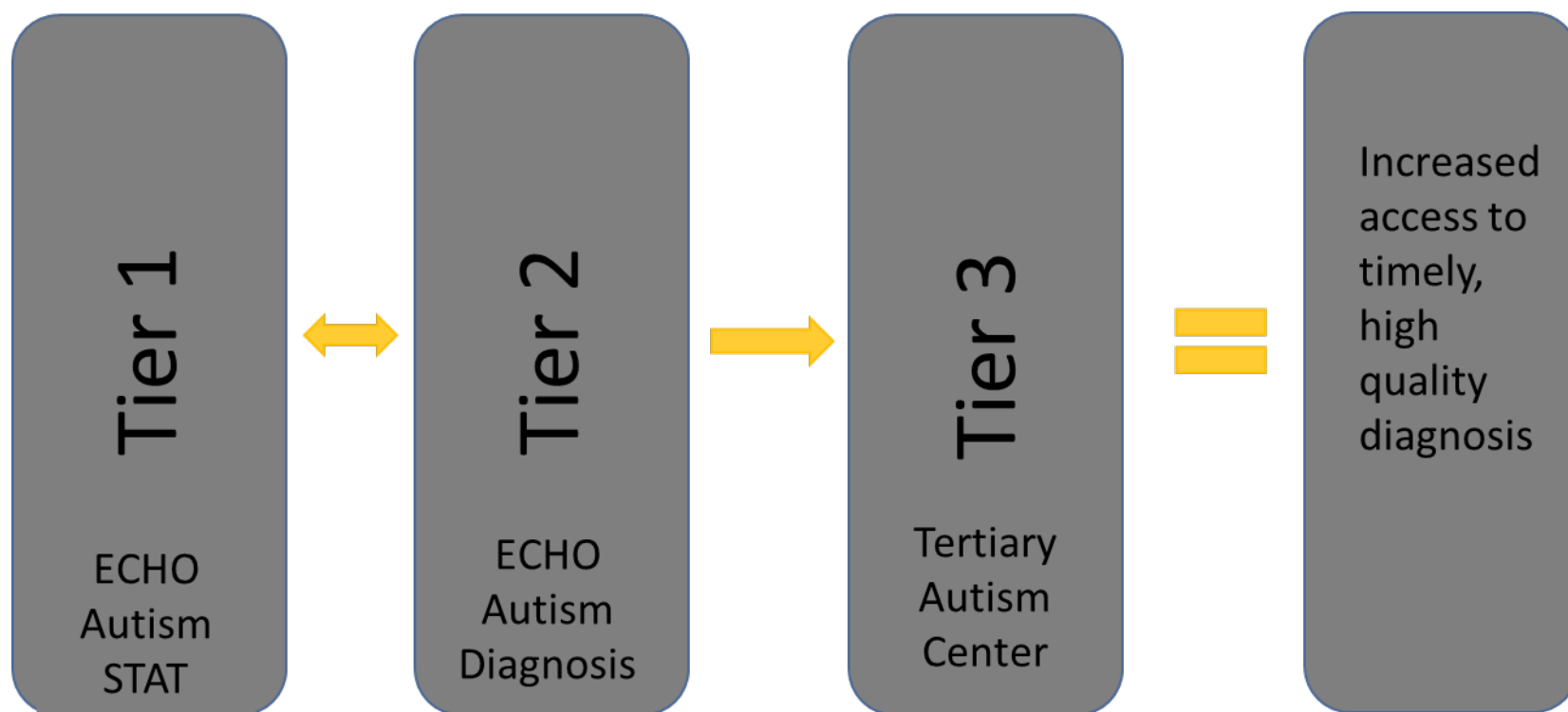To determine whether participation in ECHO Autism will result in improved:

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

	December 1, 2016	March 1, 2017	June 1, 2017	September 1, 2017	December 1, 2017	March 1, 2018	June 1, 2018	September 1, 2018
Cohort 1: Arkansas CHOP	T1: ECHO Launch	T2: 3 mo Assessments	T3: 6 mo Assessments	T4: Final Assessments				
Cohort 2: Rochester Toronto		T1: ECHO Launch	T2: 3 mo Assessments	T3: 6 mo Assessments	T4: Final Assessments			
Cohort 3: Lurie Center Vanderbilt			T1: ECHO Launch	T2: 3 mo Assessments	T3: 6 mo Assessments	T4: Final Assessments		
Cohort 4: Pittsburgh UC Irvine				T1: ECHO Launch	T2: 3 mo Assessments	T3: 6 mo Assessments	T4: Final Assessments	
Cohort 5: Cincinnati Nationwide					T1: ECHO Launch	T2: 3 mo Assessments	T3: 6 mo Assessments	T4: Final Assessments

Callouts:

- 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

The Missouri Diagnostic Model*

Right Care, Right Time, Right Place

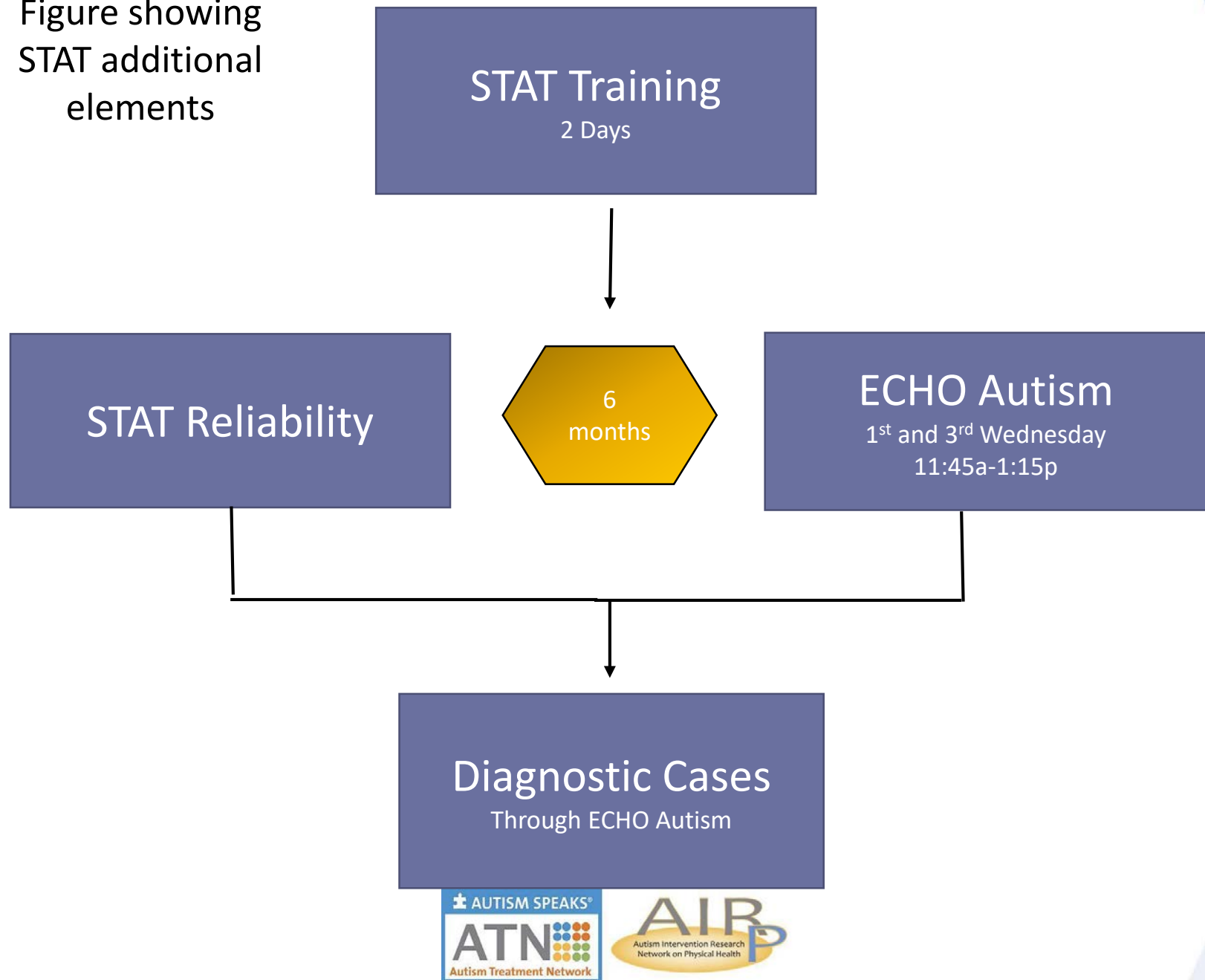| Tier 1		Tier 2		Tier 3		Increased access to timely, high quality diagnosis
ECHO Autism STAT	↔	ECHO Autism Diagnosis	→	Tertiary Autism Center	=	

*Concept being developed

Figure showing STAT additional elements

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?