

# Family Co-production of Research

## Autism Intervention Research Network on Physical Health and Autism Treatment Network

Tim Eidson

Amy Hess

Karen Kuhlthau



This activity is supported by the Health Resources and Services Administration (HHS) under cooperative agreement UA3 MC11034-01 Autism Intervention Research Network on Physical Health. This work was conducted through the Autism Speaks Autism Treatment Network serving as the Autism Intervention Research Network on Physical Health.

- **Very brief overview of the network -- Karen Kuhlthau, Network Co-Director and Principal investigator of AIR-P**
- Structure of Family involvement – Amy Hess, Family Advisory Committee Co-Chair
- Example of Family Involvement – Tim Eidson, Family Advisory Committee Co-Chair
- Researcher's perspective on Family Involvement – Karen Kuhlthau



# Autism Network

- Dedicated to improving the lives of children and their families by making high quality, comprehensive, multidisciplinary care available within local communities.
- Funding from HRSA, Autism Speaks Foundation, and PCORnet
- Clinical Coordinating Center – at Harvard/MGH
- Family Advisory Committee nationally and at each of our clinical sites
- Network Steering Committee with two Family Co-chairs as members



# Network Objectives



Research



Mentorship of New Investigators



Creating Best Practices and Standards of Care



Quality and Practice Improvement



Dissemination

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# Meet Tim and the Family



- Matt is 16 and is driving!
  - Diagnosed at 3, medication disaster, speech therapy via Skype
  - Re-evaluations, independence, employment, pending college launch
- General Pediatrician
  - Autism interest, Autism Echo, ATN-FAC Co-Chair, STAT evaluations, school advisor, Co-ordinate LIUB





# Meet Amy and the Family

**Henry:** 19, gregarious artist who just landed his first large scale commission – a billboard art project in Columbus!!

**Amy:** Behavioral Health Outreach leader with NCH; ATN/ALHN; ECHO, tired, arts boards

Henry and his family enjoy working to build health, arts, living and community opportunities for individuals with autism locally and nationally.



# Who are the Family Advisory Council Members?

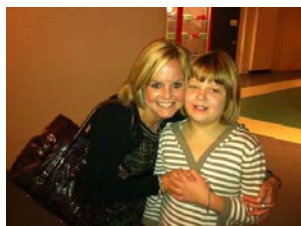
- Family as Faculty overseeing all family advisors for large hospital
- ATN Coordinators
- State department of Developmental Disabilities
- Physicians
- Triage Call RN
- Family Navigator
- Social Work, LCSW
- Teachers, transition specialists
- Dentists
- AS Walk Chairs and organizers
- Self-advocates
- Family Centered Care Coordinator
- Family Outreach Associate





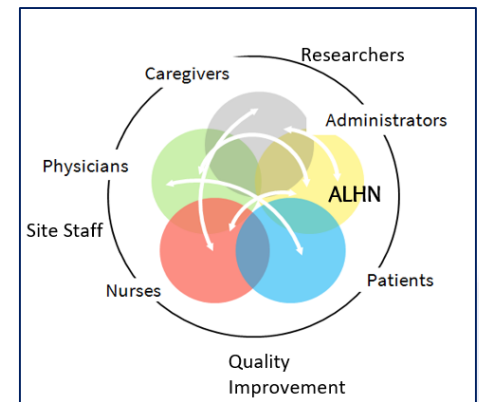
# Evolution of the FAC

- One FAC representative initially (2009)
- Additional members added (2011)
  - Co-chair roles
  - Steering committee
- Signed agreement and compensation for efforts across multiple areas



# Current Scope of Work

- National Objectives:
  - To be partners in strategic planning and goal setting network-wide to promote the Network mission and activities.
  - To engage with other Network stakeholders and develop clinical and research priorities.
  - To help develop and implement network procedures, policies, and activities.
  - To engage in quality improvement efforts and Learning Health System efforts.



# Current Scope of Work

- Local Objectives:
  - To work toward engage meaningfully in site-specific Network activities, including research, clinical care efforts, and outreach.
  - To act as an advocate and facilitate the involvement of other parents and families at your site and in your community.
  - To actively participate in the research, care, and quality improvement efforts occurring at your site and in your community.



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## Example of Family Involvement

Advocate Community Reviewer for applications for pilot studies / predoctoral fellowships for Central Auditory Processing Disorders (CAPD). Supported by the Royal Arch Masons who partnered with Autism Speaks in conducting CAPD research that benefits the ASD community

Each application was reviewed by two research professionals and an advocate community reviewer who is responsible for writing an Overall Community Impact evaluation

Group discussion with all reviewers included overall scoring by the three reviewers.

Appreciated committee leadership in underscoring parent involvement even when there may have been some level of discrepancy with professional evaluation and my input. I felt supported in voicing my opinion on the strength of community/patient impact a particular application might have in advancing diagnostic opportunities for ASD.



## ATN/AIR-P Research Family involvement

### **ATN Scientific Review Committee (SRC).**

Manuscripts for publication in scientific and medical journals describing studies conducted by and/or within the AS ATN must be reviewed by members of the AS. Various members of our FAC are involved in the SRC committee to ensure family voices are heard during manuscript review before formal submission.

### **AS/AIR-P Signature Study Committee**

To prepare, submit, and administer both internal and external research grants with the aim to decrease autism comorbidities.

FAC Members are active participants in grant development. Participates in biweekly workgroup teleconference.

Major grants co-produced by FAC members and grants including funding for remuneration for FAC involvement.



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# The Secret Life of a Researcher

- We want to do cutting edge research that will change the world.
- We have lots of rules to follow.
- But we don't know everything and we are insecure.
- We need families to keep our work grounded and impactful.
- YOU need to tell us what is important.

## Guide for Managing Constipation in Children:



A Tool Kit for Parents



## Autism and Medication: Safe and Careful Use



A Guide for Families of Children with Autism



# Moving Knowledge, Not Patients



# ECHO Autism

**Purpose:** Teach primary care providers how to take care of children with autism.

**Design:** Multisite study assessing the impact of a collaborative telehealth intervention (the ECHO Model) to provide case based learning to primary care providers

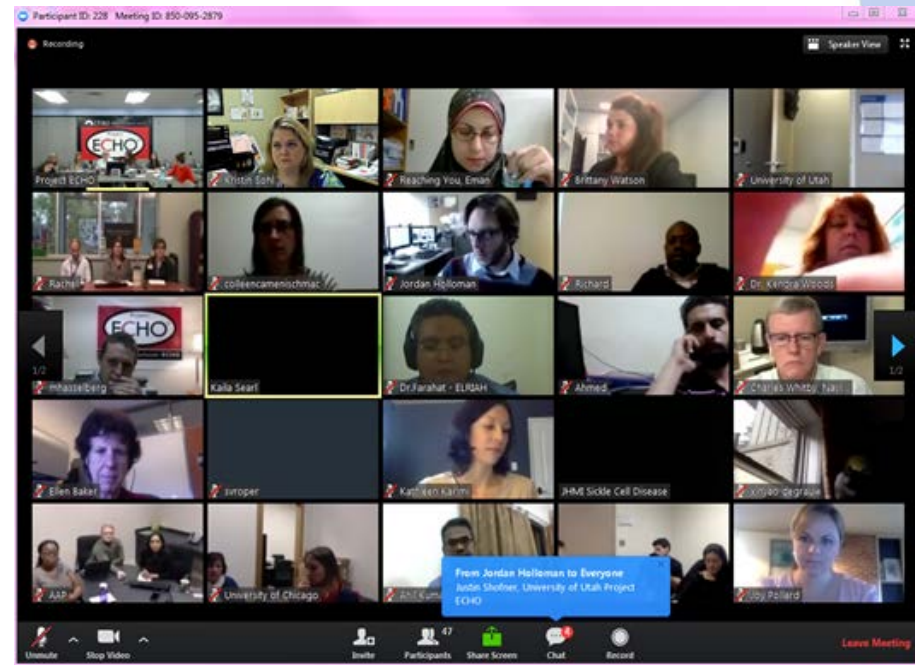
**Objective(s):** To determine whether participation in ECHO Autism will result in improved knowledge, clinical practice behavior and self-efficacy among Primary Care Providers (PCPs) in the areas of:

1. ASD screening and identification
2. Assessment and treatment of medical co-morbidities

Parent partners are involved in each site's ECHO and provide support to PCPs.



# ECHO Autism Platform



# One Researcher's Perspective

- We are learning together.
- Need to create a safe space to share and challenge perspectives.
- This partnership may be new to the researchers and new to the parents.
- Our cultures and paradigms are different but compatible.
- Long term relationships are key as work gets decided in the grant writing process.





# Parents



# Include self advocates





# Make sure that your parent partners are so welcomed that they

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Make sure that your parent partners are so welcomed that they wear their superhero capes.



# To Learn More About and Engage with the Network

Please visit our Websites!

ATN

• [www.asatn.org](http://www.asatn.org)

AIR-P

• [www.airpnetwork.org](http://www.airpnetwork.org)



# Thank you Family Voices Questions?

