Origin of ASD PEDS Network Research Studies

2013 STRATEGIC PLAN for Autism Spectrum Disorder Research

Funding Opportunity Announcement:
Services Research for Autism Spectrum Disorder across the Lifespan

NIMH FOA:
Research on Early Identification and Linkage to Services for ASD (R01)
Test the development of interventions that coordinate ASD screening, evaluation and engagement in treatment and services within the first two years of life

Emphasize reduction of disparities in outcomes for underserved populations
Research on Early Identification and Linkage to Services for ASD (R01)

Amy Wetherby, Ami Klin, Catherine Lord, Craig Newschaffer
Florida State University
Emory University
Drexel University
Weill Cornell Medical College

Wendy Stone
Univ. of Washington

Alice Carter, Radley Sheldrick
Univ. of Mass.
Boston
Tufts University

Emily Feinberg
Boston University
Yale University
CHOP

Karen Pierce
Univ of California San Diego
Southwest Autism Research & Resource Center

Amy Wetherby, Ami Klin, Catherine Lord, Craig Newschaffer
Florida State University
Emory University
Drexel University
Weill Cornell Medical College
## FIVE FUNDED RESEARCH STUDIES

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<td>Univ. of California San Diego; Southwest Autism Research &amp; Resource Center</td>
<td>Detection of ASD at the 1st birthday as standard of care: The Get SET Early Model</td>
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<td>Wendy Stone</td>
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<td>Florida State University; Emory University; Drexel University; Weill Cornell Medical College</td>
<td>Mobilizing Community Systems to Engage Families in Early ASD Detection and Services</td>
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Research on Early Identification and Linkage to Services for ASD (R01)

**Differences**

- **Settings**
- **Screening and Diagnostic Instruments**
- **Research Designs**
- **Strategies for Referral to ASD Services and Engagement**

**Commonalities**

- All studies will be entering study data into NDAR
- All studies are in a position to study health disparities
- Some studies administering same screening and diagnostic instruments

**Collectively ...**

- Approximately 70,000+ children will be screened
- Anticipate that nearly 1,000 children may be diagnosed with ASD
ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

In 2014
NIMH invited researchers to work together to form the ASD PEDS Network

Four Common Measures are Being Utilized

- Autism Diagnostic Observation Schedule (ADOS-2)
- Mullen Scales of Early Learning (MSEL)
- Vineland Adaptive Behavior Scales (VABS-II)
- Autism Centers of Excellence (ACE) Family Medical History
Since Grants were Awarded in August 2014

- Network researchers developed their own website to share instruments, treatment tracking matrices, publications
- Presentations by researchers at the IACC, IMFAR Conferences
- Conducted cross-trainings for research staff at other Network projects

“NIMH is currently supporting 5 large-scale studies on early identification of ASD …designed to address overarching questions … Such initiatives are a promising step in discerning the direct relationship of ASD screening to clinical outcomes.”
ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

Current Status

- Finishing Year 3 of their 5-year projects
- Middle of recruitment and data collection

Convened June 5-6, 2017 ASD PEDS Meeting

Identify potential scientific areas to leverage their data from the ASD PEDS Network to address research gaps

- Impact of parental / provider concern vs. no concern at screening
- Treatment Tracking: Examine pathways from screening to services
- Onset of ASD symptoms at 12, 24 and 36 months
- Implementation Project: Facilitators and barriers
**FUTURE DIRECTIONS**

- Studies will be completed in Fall 2019
- Researchers to conduct cross-site analyses
- Network researchers to co-publish findings
- Conduct joint presentations
- Explore future studies that could be conducted via the Network
- Network could present research findings at the IACC