ASD PEDS Network Meeting Convened on June 5-6, 2017

Denise Pintello, Ph.D., M.S.W.
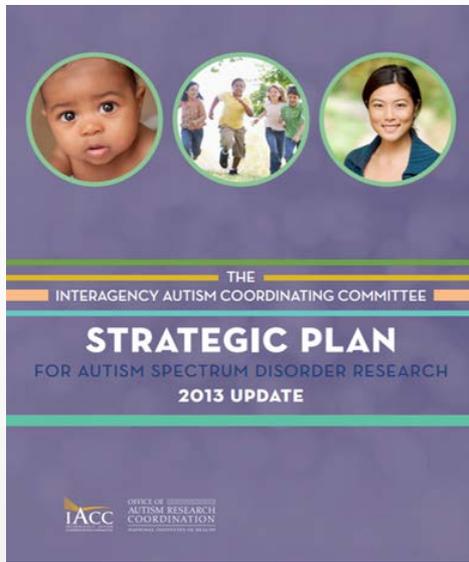*Division of Services and Intervention Research*
Chief, Child & Adolescent Services Research Program

July 26, 2017

National Institute of Mental Health
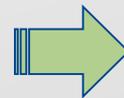
Origin of ASD PEDS Network Research Studies

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)

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)

Wendy Stone
Univ. of Washington

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

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

Emily Feinberg
Boston University
Yale University
CHOP

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

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Research on Early Identification and Linkage to Services for ASD (R01)

FIVE FUNDED RESEARCH STUDIES

	Karen Pierce	Univ. of California San Diego; Southwest Autism Research & Resource Center	Detection of ASD at the 1st birthday as standard of care: The Get SET Early Model
	Wendy Stone	University of Washington	A Screen-Refer-Treat (SRT) Model to Promote Earlier Access to ASD Intervention
	Emily Feinberg	Boston University; Yale University; Children's Hospital of Philadelphia	Early Identification & Service Linkage for Urban Children with ASD
	Alice Carter, Radley Sheldrick	University of Massachusetts Boston	Addressing Systemic Health Disparities in Early ASD Identification and Treatment
	Amy Wetherby, Catherine Lord, Ami Klin, Craig Newschaffer	Florida State University; Emory University; Drexel University; Weill Cornell Medical College	Mobilizing Community Systems to Engage Families in Early ASD Detection and Services

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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

	CARTER, ALICE	FEINBERG, EMILY	PIERCE, KAREN	STONE, WENDY	WETHERBY, AMY
Setting	Primary care & EI system	3 urban primary care systems	Primary care & EI system	Primary care & EI system	3 different community svs systems (including primary care)
Population	Urban, Low SES, Hispanic	Low-income and minority children	Diverse sample (AA, Latino); Pheonix: oldest age (5) of ASD	Underserved population (includes low SES &	Inner city, urban & rural settings; large % ethnic, minority families
Sample Size	Screen 3,885 children Screen +: ~315 ASD Diagnosis: ~236	Screen 19,500 children Screen +: ~951 ASD diagnosis ~175	Screen: 15,000 (7,500 per city) Screen +: ~820 ASD Diagnosis: ~150-300	Screen 2,660 children Screen +: ~490 ASD Diagnosis: ~90-110	Screen 36,000 children @ 18 mo (+ or - 3 mo) Screen +: ~697 ASD diagnosis: ~411 children
Age Range	14-24 months (up to 33 mo)	ic-27 mo who present @ pediatrician for 18-24 mo well-child visit	12, 18, 24 and 36 months	16-30 months	18-27 months
Initial Scrn Tool(s)	BITSEA; POSI; ACE Family Medical Hi	M-CHAT; ACE Family Medical History	CSBS; ACE Family Medical History	M-CHAT	SMART ESAC (Includes 10 broadband questions & 20 autism-specific questions)
Diagnostic Tools	STAT; MSEL ;~ ADOS-2; VABS-II	M-CHAT-FI; VABS-II; MSEL; ADOS-2	ADOS-2; MSEL; VABS-II; ADI-R	STAT; MSEL; VABS-II; ADOS-2; ACE Family Medical History	ADOS-2; SORF; MSEL; VABS-II; Home Observation; ACE Family Medical History (and other parent questionnaires)

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

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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

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ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

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

U.S. Preventive Services TASK FORCE

Autism Spectrum Disorder in Young Children: Screening
Release Date: February 2016

Recommendation Summary

Population	Recommendation	Grade (What's This?)
Children aged 18 to 30 months	The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for autism spectrum disorder (ASD) in young children for whom no concerns of ASD have been raised by their parents or a clinician.	I

JAMA The Journal of the American Medical Association

Editorial | February 16, 2016

Embrace the Complexity
The US Preventive Services Task Force Recommendation on Screening for Autism Spectrum Disorder FREE

Michael Silverstein, MD, MPH[1]; Jenny Radesky, MD[2]

"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."

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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

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ASD Pediatric, Early Detection, Engagement and Services Network (ASD PEDS)

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