



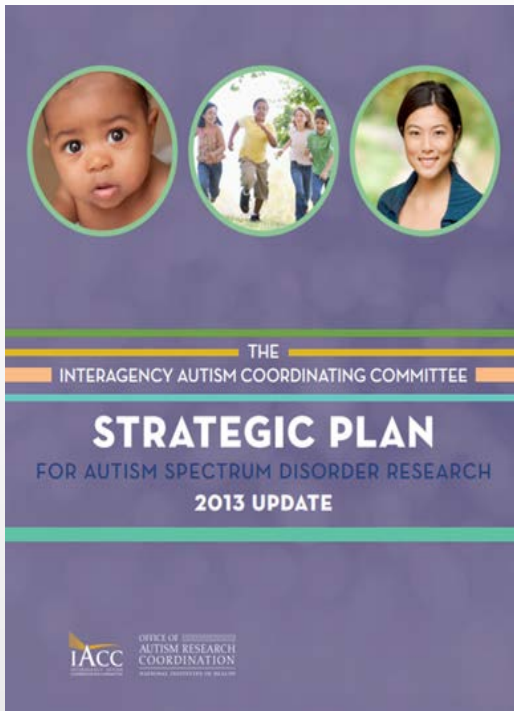
Introduction to the ASD PEDS Network

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January 17, 2018



Origin of ASD PEDS Network Research Studies

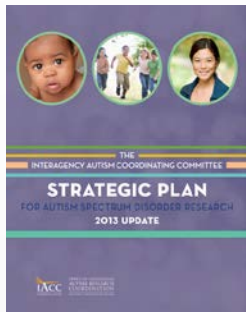


2013 STRATEGIC PLAN for Autism Spectrum Disorder Research



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

Origin of ASD PEDS Network Research Studies



2013 STRATEGIC PLAN for Autism Spectrum Disorder Research



Department of Health and Human Services

Sept 2013

Part 1. Overview Information

Participating Organization(s)	National Institutes of Health (NIH)
Components of Participating Organizations	National Institute of Mental Health (NIMH)
Funding Opportunity Title	Services Research for Autism Spectrum Disorder across the Lifespan (ServASD): Research on Early Identification and Linkage to Services for ASD (R01)
Activity Code	R01 Research Project Grant
Announcement Type	New

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

Department of Health and Human Services	
Part 1. Overview Information	
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Announcement Type	New
Related Notices	<ul style="list-style-type: none">• October 18, 2010 - See Notice NOT-09-14-003, Guidance on Resumption of NIH Extramural Activities Following the Recent Lapse in Appropriations.• August 21, 2010 - Removed reference to ASSST in section IV.C, since ASSST is currently only available for multi-project applications.• May 10, 2010 NOTICE-10-076 - NIH to Require Use of Updated Electronic Application Forms for Due Dates on or after September 25, 2010. Forms-C applications are required for due dates on or after September 25, 2010.
Funding Opportunity Announcement (FOA) Number	RFA-MH-14-100



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

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



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

FIVE FUNDED RESEARCH STUDIES



Wendy Stone

University of Washington

A Screen-Refer-Treat (SRT) Model to Promote Earlier Access to ASD Intervention




This project is testing the Screen-Refer-Treat (SRT) model, which is designed to promote earlier access to specialized intervention for toddlers with ASD among four rural and diverse communities across Washington State to evaluate changes in service delivery practices



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

FIVE FUNDED RESEARCH STUDIES



	<p>Emily Feinberg</p>	<p>Boston University; Yale University; Children's Hospital of Philadelphia</p>	<p>Early Identification & Service Linkage for Urban Children with ASD</p>
	<p>Alice Carter, Radley Sheldrick</p>	<p>University of Massachusetts Boston</p>	<p>Addressing Systemic Health Disparities in Early ASD Identification and Treatment</p>
	<p>Amy Wetherby, Catherine Lord, Ami Klin, Craig Newschaffer</p>	<p>Florida State University; Emory University; Drexel University; Weill Cornell Medical College</p>	<p>Mobilizing Community Systems to Engage Families in Early ASD Detection and Services</p>

Before Funding the R01 Projects ...

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
Selling	Primary care & EI system	3 urban primary care systems	Primary care & EI system	Primary care & EI system	3 different community svcs systems (including primary care)
Population	Urban, Low SES, Hispanic	Low-income and minority children	Diverse sample (AA, Latino); Pheonic: 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 +: " 620 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)	18-24 months present re pediatrician for 18-24 mo well-child visits	12, 18, 24 and 36 months	18-30 months	18-27 months
Initial Conn Tool(s)	BITSEA; POSI; ACE Family Medical History	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 are collecting data on health disparities
- All studies will be entering study data into NDAR
- 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

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

Since Grants were Awarded in August 2014

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



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, MPH¹; Jenny Radesky, MD²

“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

- Started Year 4 of their 5-year projects
- Reaching apex of recruitment and data collection
- Initial joint publication submitted



Convene Monthly and Annual In-Person Meetings

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

- Treatment Tracking: Examine pathways from screening to services
- Onset of ASD symptoms at 12, 24 and 36 months
- Measurement of short-term and intermediate risks and benefits of early ASD screening
- Preliminary validation of broadband screening instruments testing young children near age 12 months



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

FUTURE ACTIVITIES

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 completed research findings at the IACC
-



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



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
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