Overcoming Challenges of Early Screening for Autism in Primary Care



Amy M. Wetherby, PhD Distinguished Research Professor Laurel Schendel Professor of Communication Disorders Director, Autism Institute College of Medicine, Florida State University

Meeting of the Interagency Autism Coordinating Committee January 12, 2016 Bethesda, Maryland

Research in a Nutshell Treatment Studies of Toddlers with ASD

Early Intervention for Children With Autism Spectrum Disorder Under 3 Years of Age: Recommendations for Practice and Research

Zwaigenbaum et al. Pediatrics 2015; 136:S60-S81

- Review of 24 interventions for children with ASD < 3 years published from 2000-2013 identified comprehensive and targeted treatment models with evidence of clear benefits.
- Emphasized the central role of the parent and interventions designed to incorporate learning opportunities into everyday activities, capitalize on "teachable moments" and facilitate the generalization of skills.

Treatment Studies of Toddlers with ASD Do Not Separate Cases Recruited from Primary Care

Ascertainment Methods to Recruit Families

Referral for Suspected ASD

Screening for ASD in Early Intervention

Younger Siblings of Children with ASD

Screening for ASD in Primary Care Settings

Research in a Nutshell Treatment Studies of Toddlers with ASD

Parent-Implemented Social Intervention for Toddlers With Autism: An RCT Amy M. Wetherby, Whitney Guthrie, Juliann Woods, Christopher Schatschneider, Renee D. Holland, Lindee Morgan and Catherine Lord *Pediatrics*; originally published online November 3, 2014;

Pediatrics 2015; 136:S60-S81

Wetherby et al. (2014) – RCT of 82 toddlers diagnosed with ASD at 18 months demonstrated significant differential treatment effects of a parent-implemented intervention

- 43 toddlers were referred for suspected ASD at UM site;
 39 were recruited from screening in primary care at FSU site
- Site differences in cognitive level (=72 vs. 77 ELC on Mullen) but no site differences in treatment effects

How many children were missed?

Screener	Sample Size	Age in months	Hits	# per 1,000
CHAT Baird et al., 2000	16,235	m=18.7	33	2.03
M-CHAT Chlebowski et al., 2013	18,122	m=20.4	95	5.24
M-CHAT Stenberg et al., 2014	52,026	at 18	60	1.15
ESAT Dietz et al., 2006	31,724	m=14.9	18	0.57
ITC Wetherby et al., 2008	5,385	m=16.4	60	11.14

Selection Bias of Screening Samples for Estimates of Sensitivity and Specificity

- Intellectual ability or developmental level is an indication of how representative the sample is
- Percentage of children with average or above average IQ has increased to at least half
- Selection bias if the average developmental level is far below 75
 - Ozonoff et al. (2015): Mullen ELC=79 (*n*=38)
 - Robins et al. (2014): Mullen ELC = 68 (*n*=105)
 - Wetherby et al. (2008): Mullen ELC = 73 (*n*=60)

Need to Improve Early Identification of Developmental Disabilities

Percentage of Population Receiving Special Education or Early Intervention Services in 2007:

- School-Age Children
 6 to 17 years
- Preschool Children
 3 to 5 years

11.4%

5.7%

Infants and Toddlers
 Birth to 2 years
 2.5%

This means, 80% of children are missed.

(31st Annual Report to Congress, US DOE OSEP, 2012)

Where do we draw the line?



2nd percentile is too low to detect the 11.4% who will be eligible for special education at school age in time for early intervention.

Parent Concern & Positive Screen on the Infant-Toddler Checklist for Children with ASD (*n*=60)



Age in Months

Wetherby, Brosnan-Maddox, Peace, & Newton, 2008

Parent Concern is Less Accurate for Children at Younger Ages

- Retrospective and prospective studies of parents of children with ASD show:
 - About 75% have concerns by 24 months
 - About 50% have concerns by 18 months
 - About 30% have concerns by 12 months
- Reported concerns not usually specific to autism
- Parents are fairly accurate reporting what their child can and cannot do but not as accurate at knowing when to be concerned.

Focus Groups with Families (n=105): Overcoming Barriers to Improving Early Detection of ASD in Community Systems

Information on developmental milestones and spectrum of *autism symptoms* Stigma related to diagnosis of autism Access to services for diagnosis and intervention

Wetherby et al. (Oct. 2015) Mobilizing community systems to tackle challenges of early detection of ASD, Oral Presentation at the DEC Conference, Atlanta, GA

Birth to 5: Watch Me Thrive! Office of the Administration for Children and Families

Coordinated federal effort to help families and providers:

- Celebrate milestones.
- Promote universal screening.

Identify possible delays & concerns early.

Enhance developmental supports.

Learn the Signs. Act Early. Are these milestones contributing to the solution or the problem?

9 Months	12 Months	18 Months		
Social & Emotional				
May be afraid of strangers	Is shy or nervous with strangers	Likes to hand things to others as play		
May be clingy with familiar adults	Cries when mom or dad leaves	May have temper tantrums		
Has favorite toys	Has favorite things & people	May be afraid of strangers		
Language				
Understands "no"	Responds to simple spoken requests	Says several single words		
Makes a lot of different sounds	Uses simple gestures, like shaking head "no" or waving	Says and shakes head "no"		
Copies sounds and gestures	Makes sounds with changes in tone	Points to show someone what he wants		

Development of gestures at 9 to 16 months predicts language 2 years later

(Caselli, Rinaldi, Stefanini, & Volterra, 2012; Rowe & Goldin-Meadow, 2009; Watt, Wetherby, & Shumway, 2006)



Children should use at least 16 gestures by 16 months.

Focus Groups with Professionals (n=41): Overcoming Barriers to Improving Early Detection of ASD in Community Systems

Training on the early signs of ASD Available validated screening tools feasible for primary care Available intervention services if screening is implemented

Wetherby et al. (Oct. 2015) Mobilizing community systems to tackle challenges of early detection of ASD, Oral Presentation at the DEC Conference, Atlanta, GA





Autism Navigator is a unique collection of web-based tools and courses that uses extensive video footage to bridge the gap between science and community practice.







For parents, professionals, and anyone interested in learning about autism

Learn about evidence-based practices in our professional development courses

Professional Courses

Explore About Autism in Toddlers

Watch unique side-by-side videos that show the early signs of autism in toddlers



About Autism in Toddlers

- Our first online course FREE to the public
- For families, professionals, or anyone interested in learning about autism spectrum disorder (ASD)
- Video clips of over a dozen toddlers with ASD at 18-24 months of age

GET STARTED



WATCH PREVIEV

Courses for professionals, parents, and anyone interested in learning about autism.



About Autism in Toddlers

Our first online course free to the public is for families, professionals, or anyone interested in learning about autism spectrum disorder (ASD). You will learn about the core diagnostic features and early signs of autism in toddlers, the critical importance of early detection and early intervention, and current information on prevalence and causes of autism. This self-paced course has video clips of over a dozen toddlers with ASD at 18-24 months of age. It takes about 2 hours to go through all of the slides and videos or spend a few minutes and visit again later.

WATCH PREVIEW

GET STARTED







This 7-hour course launched in Summer, 2015.







A Seamless Path for Families

The Autism Navigator® is linked with a tiered system of online courses, tools, and resources to support families. Families are first invited for universal screening with the Smart Early Screening for Autism and Communication Disorders (ESAC) beginning at 9 months of age and to join a parent portal. This portal posts the screening report and sends invitations to the tiered system of supports for families based on the child's screening outcome. Families are invited to be re-screened every 3 to 6 months until 30 months of age. Following are the tiered supports for families:



For all families—the 16 by 16™ series of Lookbooks to help families and others learn critical social communication skills that children should reach by 16 months to help their child learn to talk.



For all families—explore video clips to learn key social communication milestones that develop from 9 to 24 months and chart their child's social communication development.



For families of children with a positive screen for autism—to learn about the early signs of autism with video clips of over a dozen toddlers with ASD at 18-24 months of age and see early intervention in action.



For families of children with a positive screen for autism who want more information—to see a library of hundreds of video clips illustrating diagnostic features and different interventions.



For families who suspect their child has ASD— to get started right away and learn intervention strategies to use in their everyday activities and support their child's learning and development.

Seamless Path for Families

For all families







What does it take to learn to talk?

It takes gestures, sounds, play... and much more.

Watch, Learn, and Spread the Word

Because the development of infants and toddlers is important to everybody.

www.FirstWordsProject.com



16 Gestures by 16 Months Lookbook now Available









Language Learning 16 Gestures by 16 Months Imagination 16 Actions with Objects by 16 Months Social Connectedness 16 Ideas to Communicate by 16 Months Cooperation 16 Ways to Manage Emotions by 16 Months Critical Thinking 16 Messages to Understand by 16 Months Copyright © 2016. The Florida State University. All rights reserved.

10 MONTHS: REACH, RAISE ARMS



At 10 months, children learn through exploration and experiences with others as they reach to take an object ...

16 GESTURES BY 16 MONTHS



16by16

10 MONTHS: REACH, RAISE ARMS

then, with an open hand facing up, ...

16 GESTURES BY 16 MONTHS





16by16

10 MONTHS: REACH, RAISE ARMS



16 GESTURES BY 16 MONTHS







Home About

Guided Tour

Get Started



Social Communication Growth Charts Learn the milestones. Launch language early.





Home About

Guided Tour

Get Started

Select Explore or Chart



Learn the milestones. Support your child's development.

Start Exploring



Seamless Path for Families

For all families



For families of children with a positive screen for autism







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www.AutismNavigator.com

ASD PEDS Network Meeting ASD Pediatric Early Detection, Engagement & Services Network



Services Research for Autism Spectrum Disorder across the Lifespan

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

Carter, Alice S; Sheldrick, Radley

Addressing Systemic Health Disparities in Early ASD Identification & Treatment University Of Massachusetts Boston

Feinberg, Emily Early Identification & Service Linkage for Urban Children with Autism Boston University Medical Campus

Pierce, Karen Detection of ASD at the 1st Birthday as Standard Of Care: The Get SET Early Model University of California San Diego **Stone, Wendy** A Screen-Refer-Treat (SRT) Model to Promote Earlier Access to ASD Intervention University of Washington

Wetherby, Amy; Klin, Ami; Lord, Catherine; Newschaffer, Craig

Mobilizing Community Systems to Engage Families in Early ASD Detection and Services Florida State University, Emory University, Weill Cornell Medical College, Drexel University