

Engaging Families of Children with Developmental Disabilities in Early Detection, Early Intervention, and Prevention



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*Strategies for Scaling Tested and Effective Family-Focused Preventive Interventions
to Promote Children's Cognitive, Affective, and Behavioral Health*

April 2, 2014

Washington, DC

AUTISM INSTITUTE

The Florida State University College of Medicine

CARD

Center for Autism and
Related Disabilities

FIRST WORDS[®]
PROJECT

SCERTS
Classroom  Intervention

esi

Early Social Interaction Project

Autism
NAVIGATOR[®]

Problem: The estimated lifetime society cost is \$3.2 million per child with autism

Autism spectrum disorder is no longer uncommon
1 in 68 children– 1 in 42 boys, 1 in 189 girls

The median age for diagnosis of ASD in the US is
over 4 years of age

Intervention has the greatest impact on autism if
it begins before 3 years of age

There is a federal mandate for early intervention, but
80% of children who need early intervention are missed.

(CDC, 2014; NRC, 2001; USDOE, 2012)

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 11.4%
- Preschool Children
3 to 5 years 5.7%
- Infants and Toddlers
Birth to 2 years 2.5%

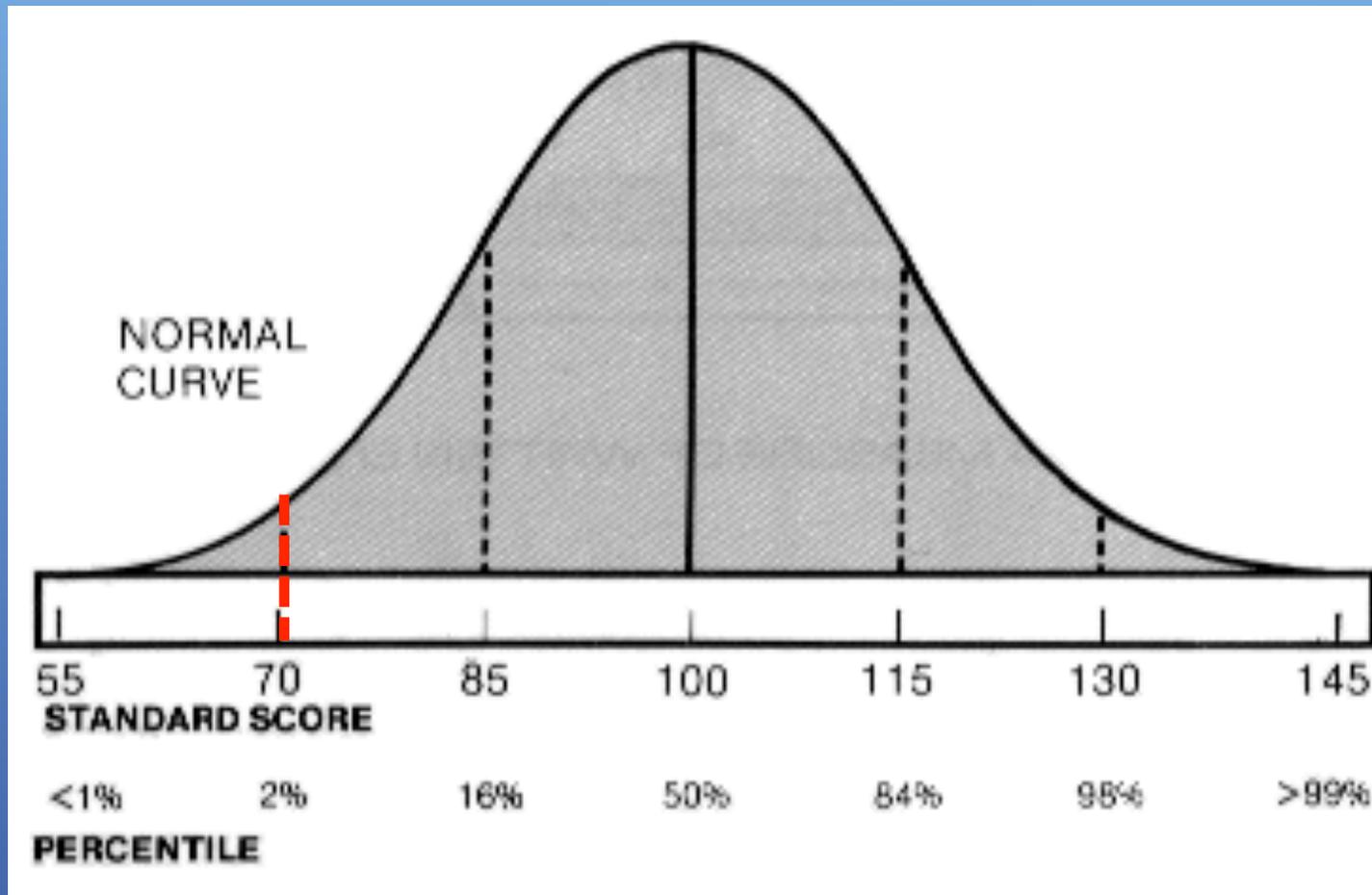
(31st Annual Report to Congress, US DOE OSEP, 2012)

Percentage of students ages 6-21 served under IDEA

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

<u>Disability Category</u>	<u>% Served</u>
Specific Learning Disabilities	43.6
Speech or Language Impairment	19.2
Other Health Impairments	10.5
Intellectual Disabilities	8.3
Emotional Disturbance	7.3
Autism	4.3
Multiple Disabilities	2.2
Developmental Delay	1.5
Hearing Impairments	1.2
Orthopedic Impairments	1.0
Visual Impairments	0.4
Traumatic Brain Injury	0.4
Deaf-blindness	0.03

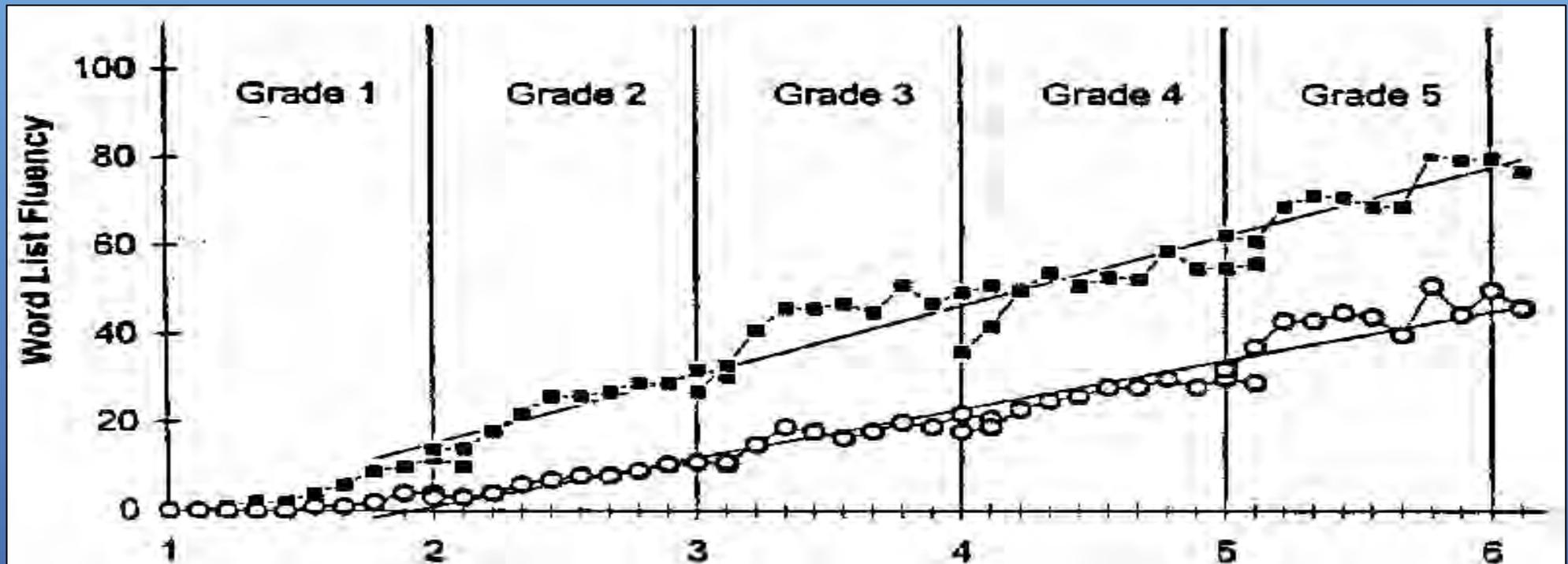
Where do we draw the line?



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.

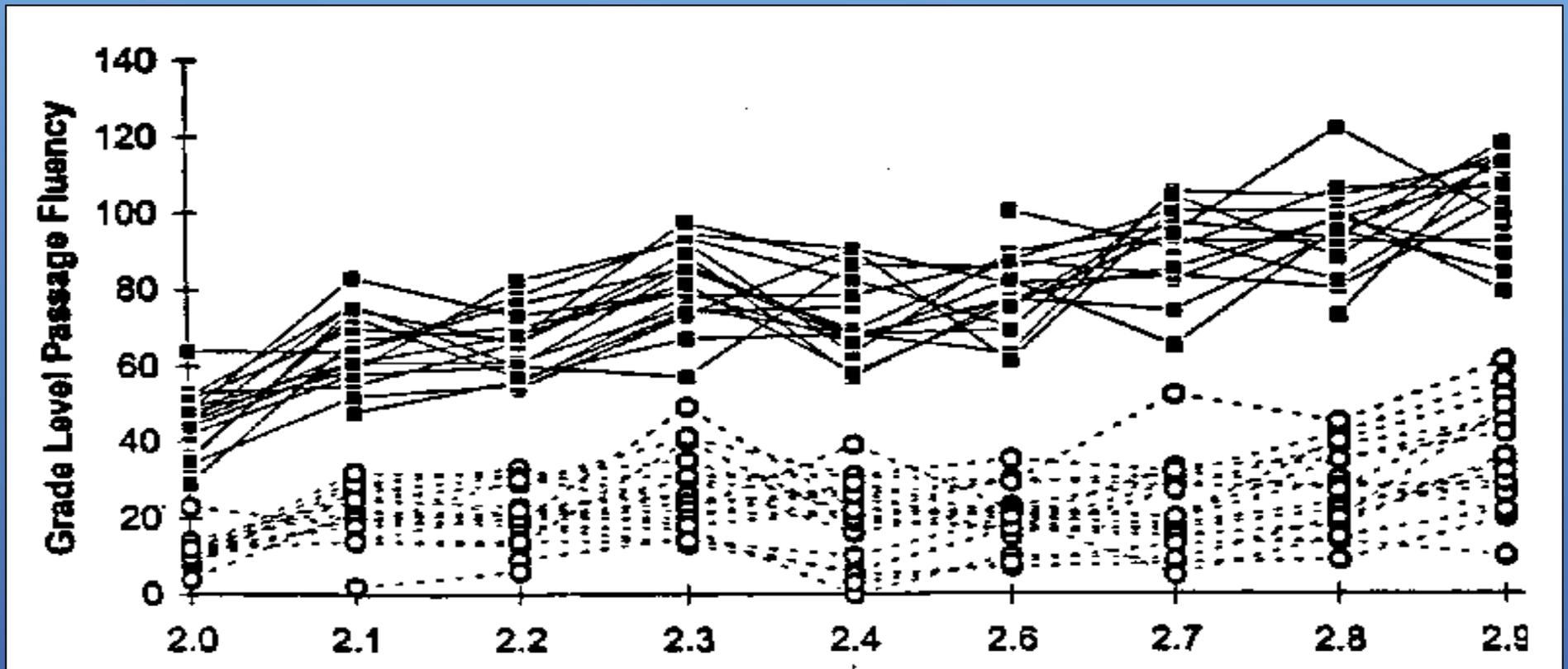
Why worry about early literacy skills?

(Good, Simmons, & Smith, 1998)



Reading trajectories are established early.

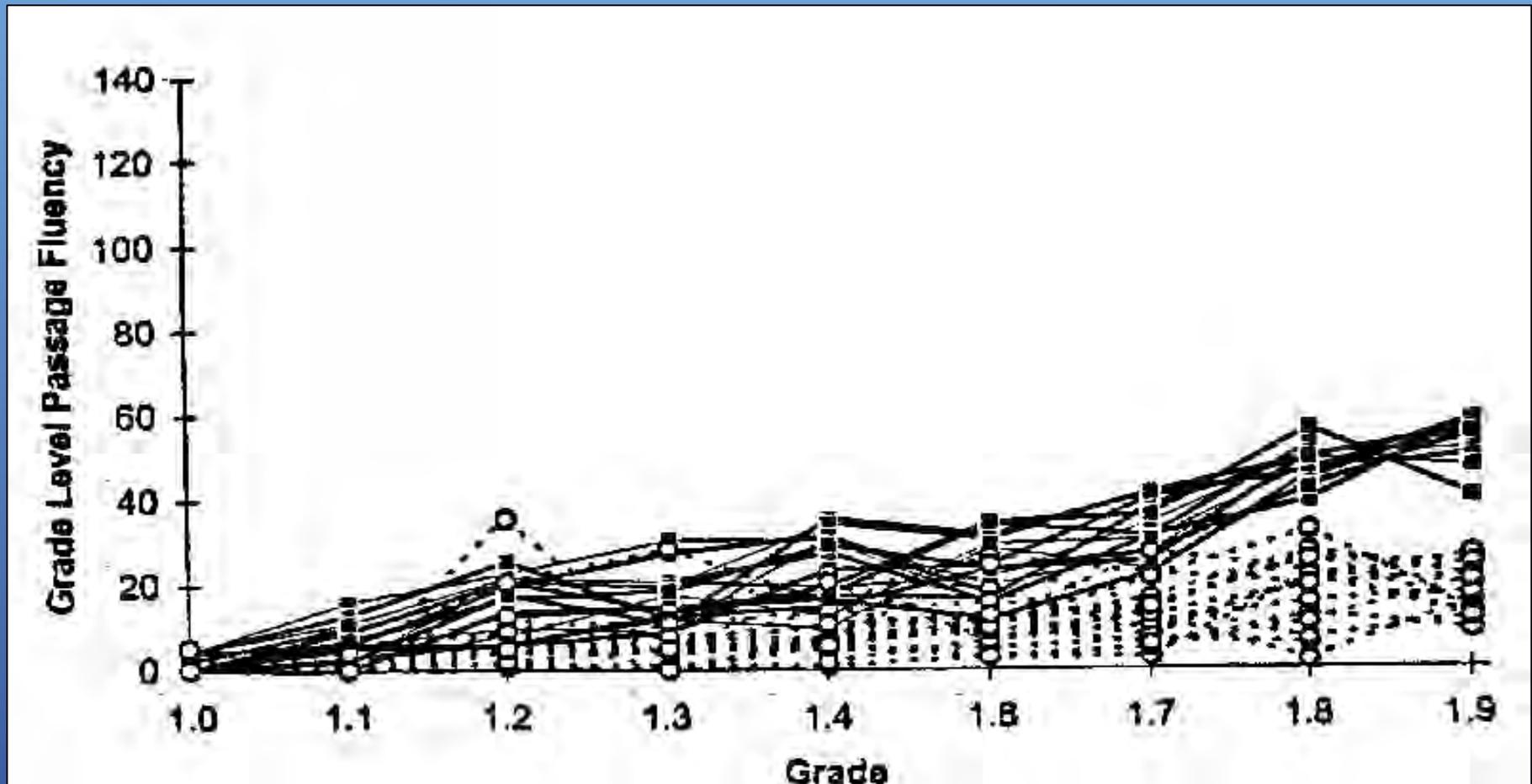
Established reading trajectories are difficult to change. *(Good, Simmons, & Smith, 1998)*



Poor readers begin with lower scores and progress at slower rates.

Traditional reading tests identify reading trajectories too late.

(Good, Simmons, & Smith, 1998)



Preschool Emergent Literacy Predictors of Reading Problems

(Lonigan, Burgess, & Anthony, 2000)

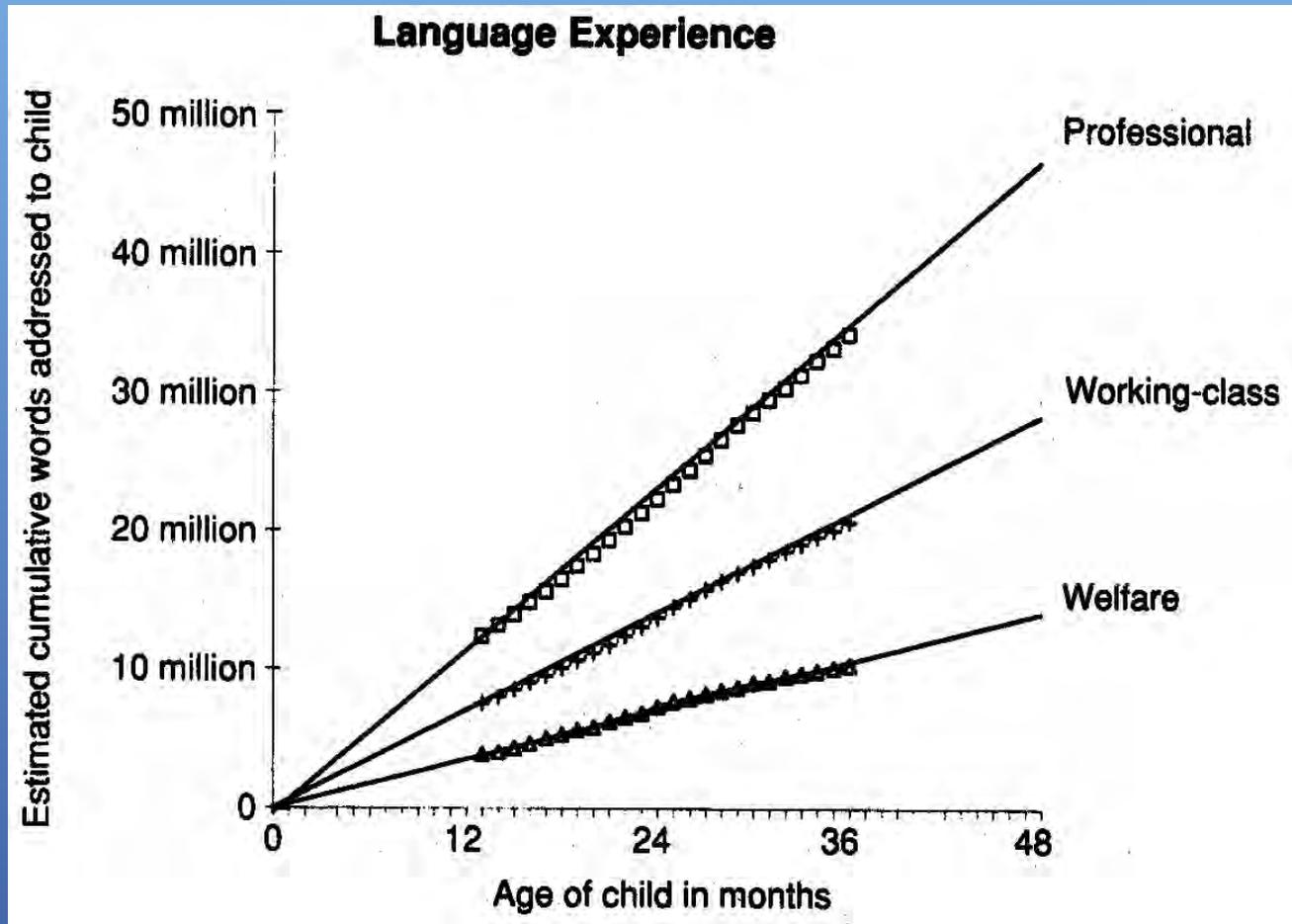
Phonological Sensitivity

Print Knowledge

Spoken Language

30 Million Word Gap

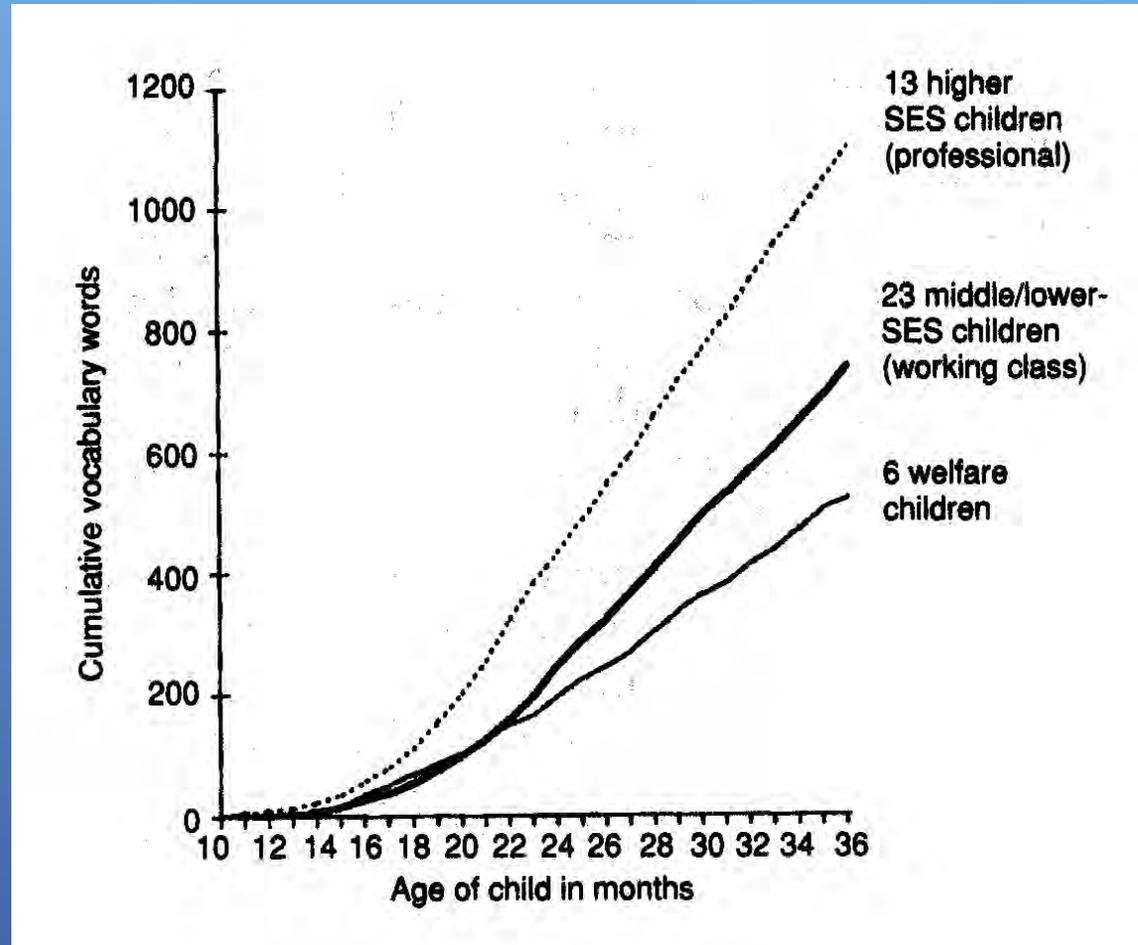
(Hart & Risley, 1995; 2003)



Cumulative differences in language experiences may be insurmountable by age 4.

Vocabulary growth trajectories are established early.

(Hart & Risley, 1995; 2003)



Widening Gap in Vocabulary Growth by Age 3

School readiness efforts need to begin earlier

- A child's rate of language acquisition is solidified by 2 to 3 years of age and is correlated with IQ and school success.



(Hart & Risley, 1995; 2003; Walker, Greenwood, Hart & Carta, 1994)

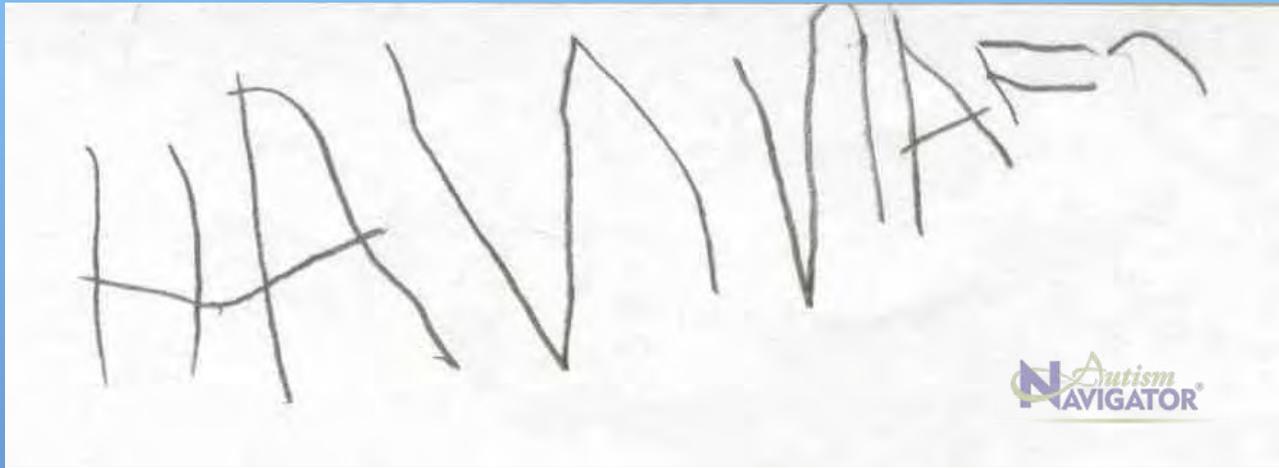
Based on a study of 1,300 students with disabilities 6-9 years of age from 180 school districts:

*“Research shows that there is a strong correlation the **number of hours** that a student spends in the **general education classroom** and **achievement outcomes** for both reading and math.”*

(Cosier, Causton-Theoharis, & Theoharis, 2013)

Which child will have challenges learning to read and write?

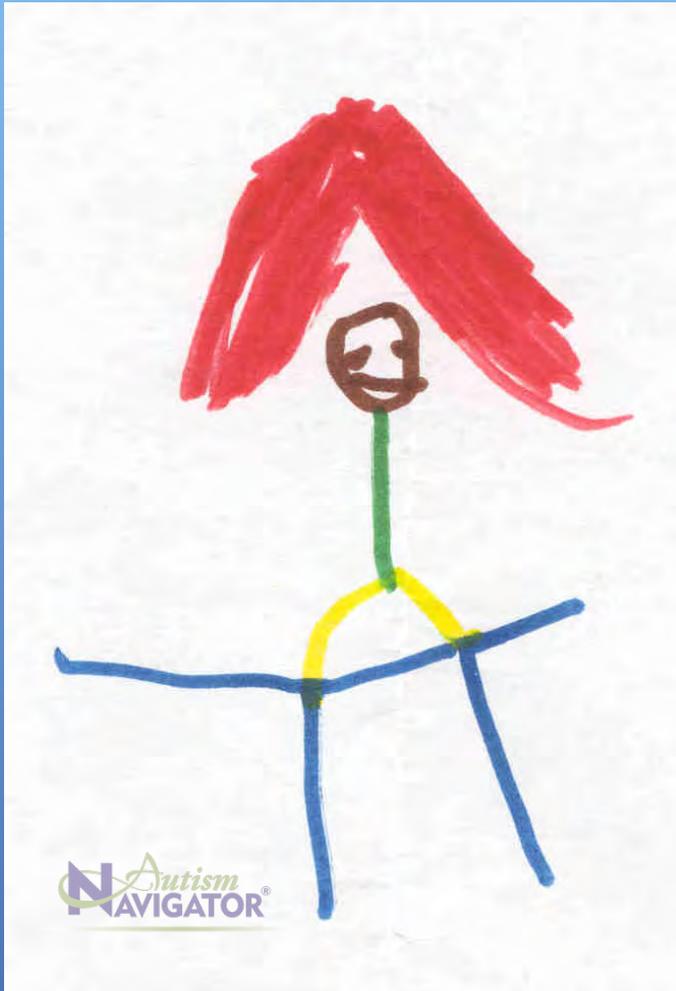




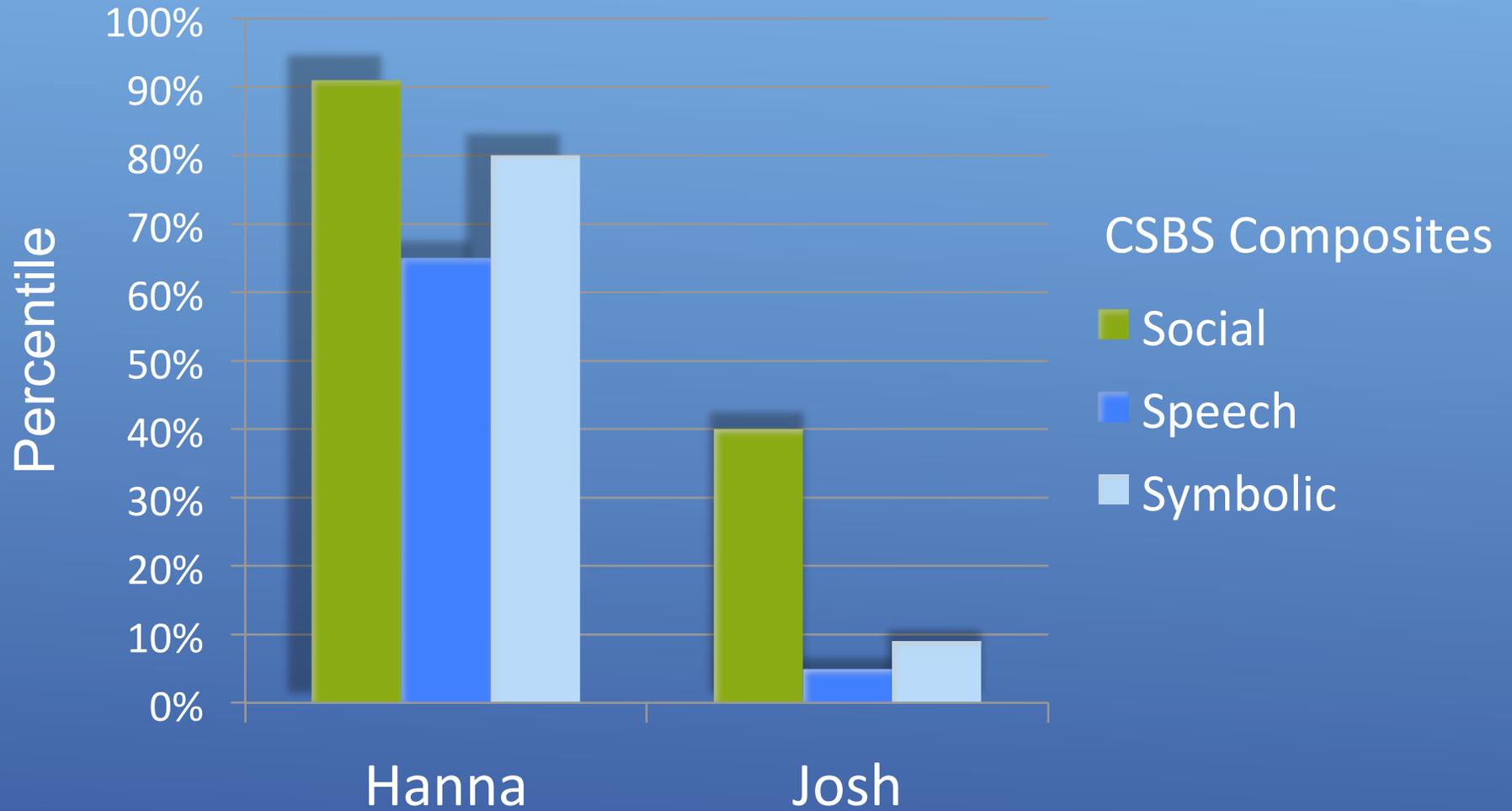
We can predict from their writing samples at 4 years of age.



We can predict from
their drawing samples
3 years of age.



We can predict from their social communication profiles at 20 months of age.





Instead of waiting to see if a child is delayed in language and at risk for reading problems, it is possible to evaluate skills that are early predictors of language development.

FIRST WORDS

Project

Longitudinal Research Project

Funded by US DOE, NIDCD,
NICHD, and CDC



firstwords.fsu.edu

Amy M. Wetherby, Ph.D.

Project Director

Research has identified a collection of 8 *predictors* of language learning.

(Watt, Wetherby, & Shumway, 2006; Wetherby et al., 2003; 2007)

Share attention and interests

Rate of communicating

Reasons for communicating

Inventory of gestures

Inventory of sounds

Understanding words

Play actions

Book knowledge



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)

Gives,
Shakes Head

Shows, Waves

Claps,
Blows a Kiss

Nods Head,
Thumbs Up



Reaches,
Raises Arms

Points with
Open Hand,
Taps

Points with
Index Finger,
Shhh

Other
Symbolic Gestures

Children should use at least 16 gestures by 16 months.



16by16™

Gestures





The richest moments for early language learning are when...



1. the child and caregiver are sharing attention, and

2. the caregiver talks about the child's focus of attention.



(Landry, Smith, Swank, & Guttentag, 2008)



A child's social communication skills—as shown here in the use of gestures and knowledge that pictures in the book convey information to share—provide critical opportunities for the caregiver to be responsive and moments for language learning. Delays in social communication impact the language learning environment.



How early can we detect autism?



Smart ESAC to streamline screening

Early Screening for Autism & Communication Disorders

- Online automated scoring at well-child checkups
 - ✓ Best 10 questions to sort out TD
 - ✓ Best additional 20 questions to sort out ASD and DD
- Algorithms for 12-18, 18-24, 24-36 months
- Se .88, Sp .81; AUC .92



Funded by NIH/NICHHD

SORF - new observational screening tool

Systematic Observation of Red Flags of Autism Spectrum Disorder

The SORF is an observational screening tool. We are testing cut-off scores for use in clinical and home observations.

In the next slide, you can preview a pair of videos that compare a child with typical development & a child with red flags of ASD.

These videos are from About Autism, our first Autism Navigator tool for the public, that will be launched in Summer, 2014



Systematic Observation of Red Flags of Autism Spectrum Disorder (SORF- Checklist)
Amy M. Wetherby, Juliann Woods, David McCoy, & Sheri Stronach

A. Impairment in Social Communication and Social Interaction	B. Restricted and Repetitive Patterns of Behavior, Interests, or Activities
1. Deficits in Social-Emotional Reciprocity	1. Repetitive and Stereotyped Behavior
<input type="checkbox"/> Limited sharing warm, joyful expressions	<input type="checkbox"/> Repetitive movements with objects
<input type="checkbox"/> Flat affect or reduced facial expressions	<input type="checkbox"/> Repetitive movements or posturing of body
<input type="checkbox"/> Limited sharing interests and enjoyment	<input type="checkbox"/> Repetitive speech or intonation
<input type="checkbox"/> Lack of response to name or social bids	2. Excessive Adherence to Routines and Ritualistic Behavior
2. Deficits in Nonverbal Communication Used for Social Interaction	<input type="checkbox"/> Ritualized patterns of behavior
<input type="checkbox"/> Poor eye gaze directed to faces	<input type="checkbox"/> Marked distress over change
<input type="checkbox"/> Limited use of conventional gestures—showing and pointing	3. Restricted, Fixated Interests Abnormal in Intensity or Focus
<input type="checkbox"/> Uses person's hand/body as a tool without gaze	<input type="checkbox"/> Excessive interest in particular objects, actions, or activities
<input type="checkbox"/> Limited use of consonant sounds in vocal communication	<input type="checkbox"/> Clutches particular objects
<input type="checkbox"/> Limited coordination of nonverbal communication	<input type="checkbox"/> Sticky attention to objects
3. Deficits in Relationships with People Other than Caregivers	<input type="checkbox"/> Fixated interests on parts of objects
<input type="checkbox"/> Less interest in people than objects	4. Hypo- or Hyper-Reactivity to Sensory Input or Unusual Sensory Interest
<input type="checkbox"/> Limited sharing of imaginative play	<input type="checkbox"/> Lack of or adverse response to specific sounds, textures, or other sensory stimuli
Adapted from the DSM-5 Diagnostic Criteria for ASD (American Psychiatric Association, 2013)	<input type="checkbox"/> Unusual sensory exploration or excessive interest in sensory aspects of environment

Recognizing Social Communication Features

Typical Development	Cause for Concern
	
Charlie at 16 months	Luke at 15 months



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Click to watch each video. (Internet connection required)

Early Social Interaction Project

Community-viable intervention model
for toddlers with ASD & their families



esi.fsu.edu

Funded by
NIMH and
Autism Speaks

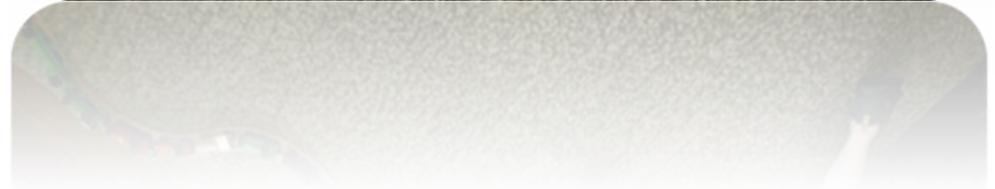


Teach parents how to use supports
and strategies in everyday activities
at home and in the community



Intensity matters...

...so how do we achieve 25 hours per week in which the child is engaged *actively* and *productively* in meaningful activities?



RCT of Early Social Interaction (ESI) Project

82 children entered study at 18 months with diagnosis of ASD

Compared effects of 2 parent-implemented intervention conditions (9 months)

● Individual ESI

- ✘ High Intensity
- ✘ 3 individual sessions per week (2 at home and 1 in clinic playroom); reduced to 2 sessions per week in last 3 months

● Group ESI

- ✘ Low Intensity
- ✘ 1 group session per week (1 education meeting and 3 playgroup sessions per month)

Employed a crossover design so that all families received both treatments.

The 3 Layer Cake:

Teaching strategies & supports to parents to promote child active engagement in everyday activities

Supports for better skills

- ◆ Model and build language, play & interaction
 - ◆ Extend activity, child's roles, & transitions
 - ◆ Adjust expectations & supports
- ◆ Balance of interaction and independence

Supports for social reciprocity

- ◆ Promoting initiation
- ◆ Balance of turns
- ◆ Natural reinforcers
- ◆ Clear message to ensure comprehension

Supports for a common agenda

- ◆ Motivating activity
- ◆ Productive roles
- ◆ Predictability
- ◆ Positioning
- ◆ Follow child's attentional focus

“Everyday Activity Categories” to promote learning in the natural environment

<p>Play with People Social Games like Peek-a-boo, Rough and Tumble, Songs & Rhymes</p>	<p>Play with Toys Blocks, Puzzles, Sand box, Playdough, Cars and Trucks, Ball Games, Baby Dolls</p>
<p>Meals and Snacks Preparation, Eating, Cleanup</p>	<p>Caregiving Dressing, Diaper Change, Bath, Washing Hands, Brushing Teeth</p>
<p>Book Sharing</p>	<p>Family Chores Mailbox, Laundry, Care for Pets, Plants</p>











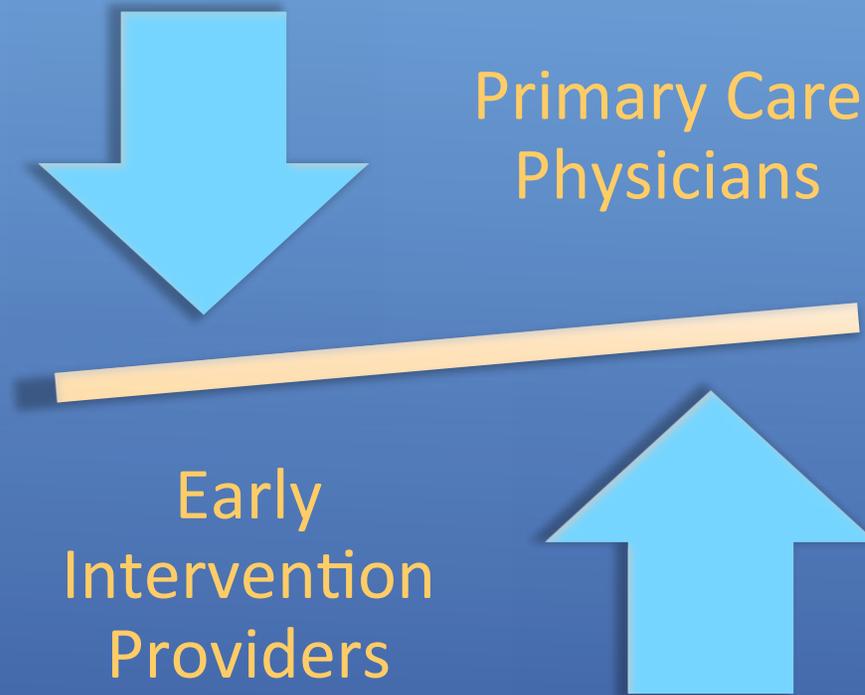




Next Steps

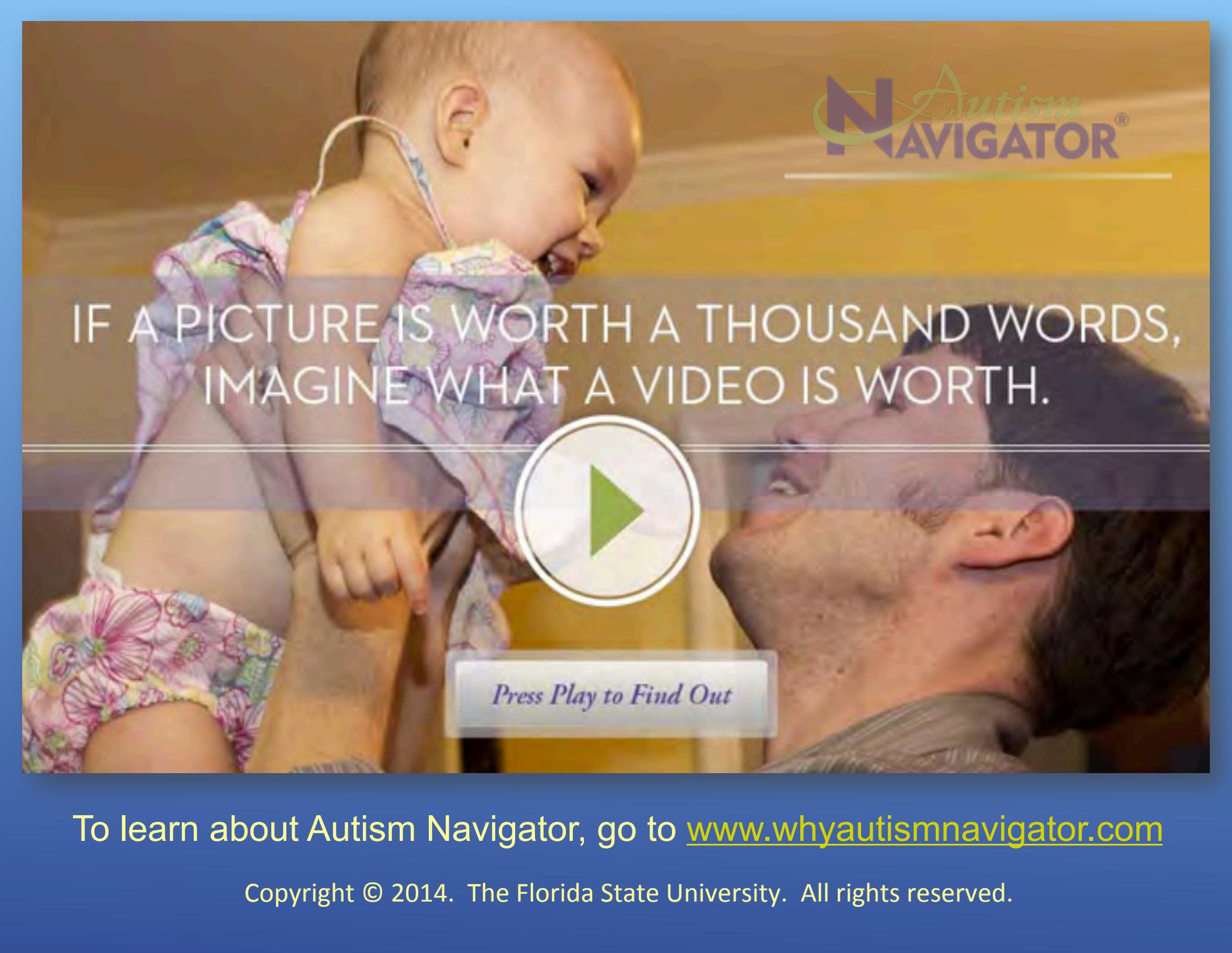
- Sorting out active ingredients of treatment and treatment responders
- Collaborating with Dr. Ami Klin, PI of the Emory Autism Center of Excellence, to study the effects of ESI with younger sibs starting at 12 months
- Comparing mobile coaching with face-to-face coaching and combinations of the two
- Developing treatments that are feasible for families of diverse cultures and communities of modest resources
- Studying community implementation strategies to bridge gap between research and common practice in both early detection and early intervention

Push-Pull: Building the Capacity of Communities to Improve Early Detection & Access to Care



Leveraging the Laws of Motion to Generate Forward Movement:
We need all 3 wheels for balance and acceleration.



A photograph of a man in a grey shirt holding a baby in a colorful floral onesie. The man is looking up at the baby with a joyful expression. The background is a warm, yellowish-gold color.

IF A PICTURE IS WORTH A THOUSAND WORDS,
IMAGINE WHAT A VIDEO IS WORTH.



Press Play to Find Out

To learn about Autism Navigator, go to www.whyautismnavigator.com



Nonverbal behaviors are those things people do to convey or exchange information or express emotions without the use of words. These include **eye gaze** (looking at the face of others to check and see what they are looking at and to signal interest in interacting), **facial expression** (movements of the face used to express emotion and to communicate with others nonverbally), **body postures** (movements and positioning of the body in relation to others), and **gestures** (hand and head movements used to signal to someone else, such as a give, reach, wave, point, or head shake). In the first year of life, children learn to coordinate nonverbal behaviors to regulate social

Overview

Social Interaction

Communication

Repetitive Behaviors and Restricted Interests

Regulatory and Sensory Systems

Treatments

Outcomes

Nonverbal Behaviors | Engaging in Interaction | Sharing Attention | Social Reciprocity

▼ TYPICAL



Typical child at 12 months shifts his eye gaze from the windup toy to the clinician, and then he coordinates his eye gaze with smiling. A child should acquire this important nonverbal behavior in the first year of life.

Nonverbal Behaviors: Eye Gaze, Facial Expression, Body Postures, and Gestures

1 2 3 4 5 6

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▼ RED FLAGS FOR ASD



Child with ASD at 18 months becomes focused on the windup toy and does not look at or engage in interaction with adults. He becomes frustrated easily, though he does not use eye gaze or gestures to convey his emotions.

POWERED BY WHITEBLIX

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► Glossary of Terms & Sources

We launched the ASD Video Glossary in 2007. You can explore it at:
www.autismspeaks.org/what-autism/video-glossary



Collection of Web-based Tools & Courses to Bridge the Gap between Science and Community Practice



Unit 1: Improving Early Detection

This unit will review the core diagnostic features of autism, help you identify early signs of autism, and understand how core features of autism impact development.



Slide 1 of 68

[View Index](#)

[Begin Unit](#)

Program Introduction

Unit 1: Improving Early Detection

Unit 2: Collaborating With Families

Unit 3: Developmental Perspectives

Unit 4: Evidence-Based Intervention Strategies

Unit 5: Addressing Challenging Behaviors

With funding from 4 founding states- FL, PA, TN, & GA- we developed this 30-hour professional development course for early intervention providers. It is being deployed in these 4 states.

Course Introduction

1. Core Diagnostic Features

2. Prevalence and Cause

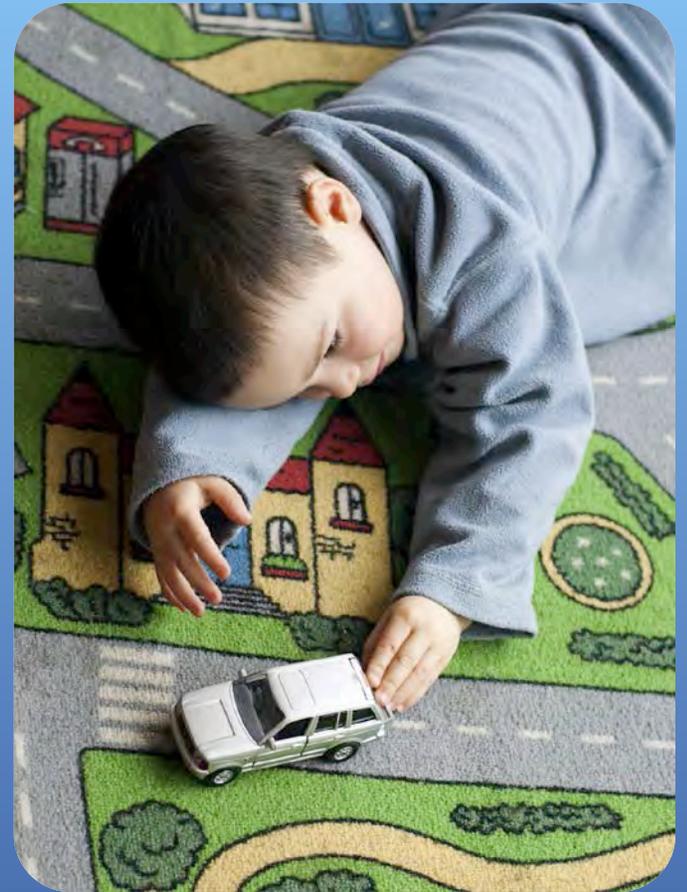
3. Early Detection

4. Collaborating with Families

5. Screening & Referral

6. Early Intervention Basics

This 6-hour course is under development. We will begin deployment in the Summer, 2014.



Welcome to the Smart ESAC, Dr. Doolittle

[Autism Navigator® for Primary Care Physicians](#)

[Manage Patients](#)



[Introduction to Smart ESAC](#)

The Introduction provides a brief overview of the Smart ESAC, an explanation of the navigation and acknowledgments.

[Continue](#)

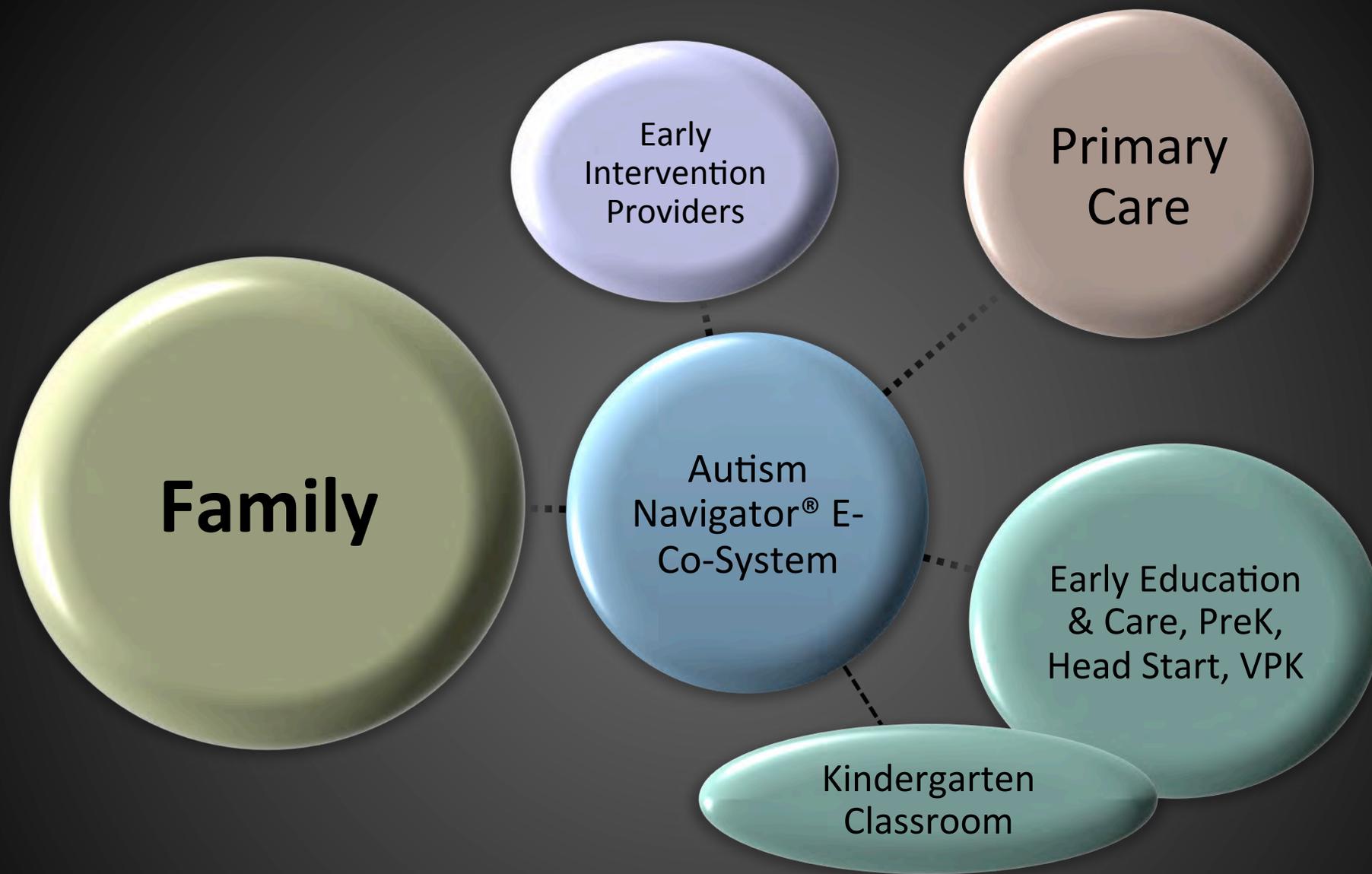
The Autism Navigator for Primary Care includes access to the Smart ESAC for universal screening for communication delay and autism between 12 and 26 months of age.

Current Courses

- ✓ for Early Intervention Providers (30 hours)
 - State Department of Education or Health
- ✓ for Primary Care (2 to 6 hours)
 - Private Insurance, Medicaid, WIC, Military

Future Courses

- ✧ for Kindergarten Classrooms (20 hours)
- ✧ for Head Start and Early Head Start
- ✧ for Early Education and Child Care, VPK, and Preschool Education



- ✓ ASD Video Glossary
- ✓ About Autism

Future Tools

- ✧ Social Communication “Growth Charts” App
- ✧ “How to” Guide for Families
- ✧ Going out to Everyday Places
 - Grocery stores, restaurants, parks, libraries, department stores, religious or public gathering places, theme parks, out-of-town travel by plane, bus, or train
 - App for Families and Course for Employees
- ✧ “GPS” after the Diagnosis



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About Autism, our first tool for the public, will be launched in Summer, 2014. In the next two slides, you can preview videos from About Autism.



Red flags for autism - Nicholas, 16 months



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Click to watch video on the early signs of autism. (Internet connection required)

Critical Importance of Early Intervention

Brandon - Change with Intervention

26 months to 31 months

32 months to 3 years

LB - Change with Intervention

20 months to 27 months

3 years to 5 years

Click to watch video of LB's change with intervention. (Internet connection required)

Social Communication Growth Charts

for all families with children 9-24 months of age



Most parents and professionals are familiar with early motor milestones. However, few know the social communication milestones, which offer a critical window into an infant's well being and are the earliest signs of healthy development and school readiness.

Play

Language
• gestures to conversation

**Social
Competence**

**Emotional
Regulation**

**Self-
Directed
Learner**

Social Communication Growth Charts

with video to illustrate the milestones and provide tips to promote development



“How To Guide”

for families of toddlers suspected of ASD

Interactive web-based program with video illustrations

Teaching Strategies and Supports: The 3 Layer Cake

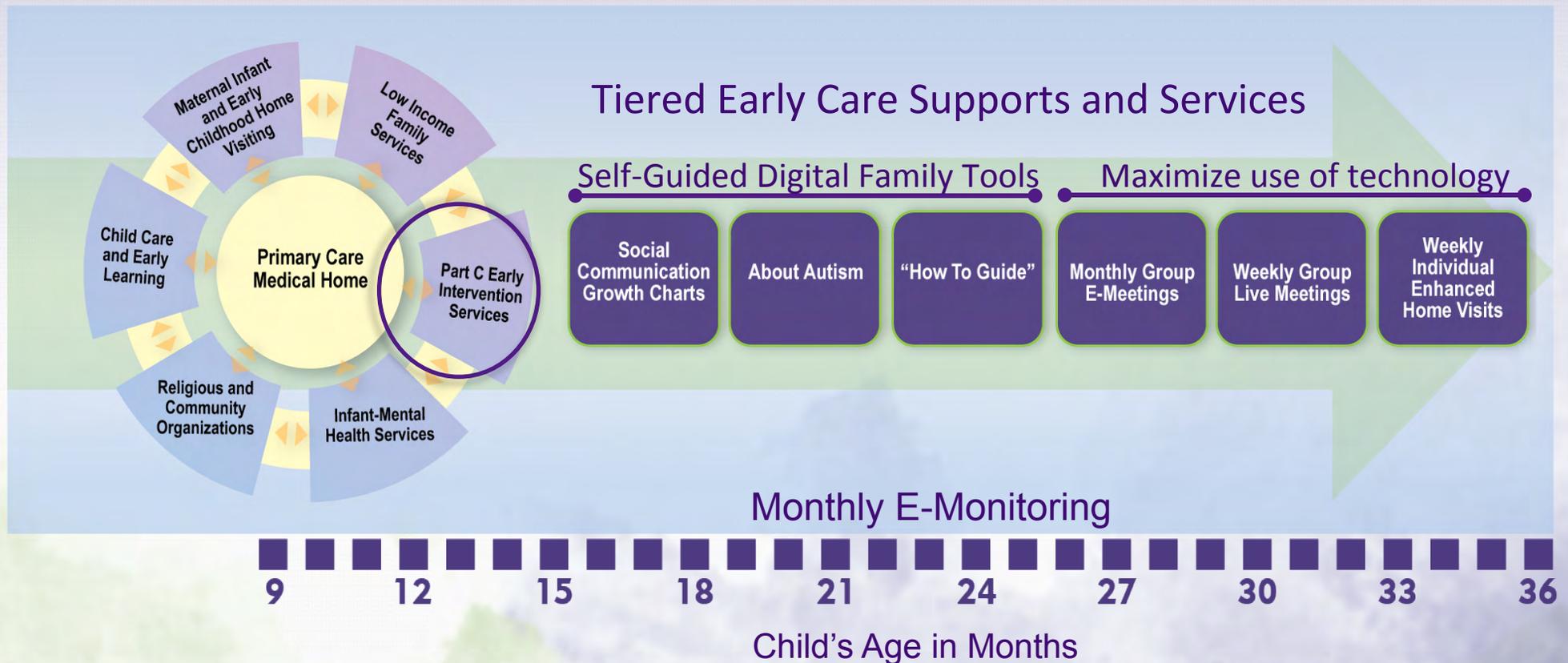


Autism Navigator E-Co-System

Autism Navigator for Primary Care

- *Smart ESAC universal screening*

Autism Navigator for Early Intervention Providers



(Adams, Tapia, & the Council on Children with Disabilities, 2013)



CLINICAL REPORT

Early Intervention, IDEA Part C Services, and the Medical Home: Collaboration for Best Practice and Best Outcomes

Richard C. Adams, MD, Carl Tapia, MD, and THE COUNCIL ON CHILDREN WITH DISABILITIES

KEY WORDS

Part C, IDEA, medical home, children with special health care needs, CSHCN, collaboration, comanagement, coaching, learning in the natural environment

ABBREVIATIONS

AAP—American Academy of Pediatrics

EI—early intervention

IDEA—Individuals With Disabilities Education Act

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The guidance in this report does not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

abstract

FREE

The medical home and the Individuals With Disabilities Education Act Part C Early Intervention Program share many common purposes for infants and children ages 0 to 3 years, not the least of which is a family-centered focus. Professionals in pediatric medical home practices see substantial numbers of infants and toddlers with developmental delays and/or complex chronic conditions. Economic, health, and family-focused data each underscore the critical role of timely referral for relationship-based, individualized, accessible early intervention services and the need for collaborative partnerships in care. The medical home process and Individuals With Disabilities Education Act Part C policy both support nurturing relationships and family-centered care; both offer clear value in terms of economic and health outcomes. Best practice models for early intervention services incorporate learning in the natural environment and coaching models. Proactive medical homes provide strategies for effective developmental surveillance, family-centered resources, and tools to support high-risk groups, and comanagement of infants with special health care needs, includ-

NAutism **NAVIGATOR**® LLC for Global Deployment

Business Model Like Newman's Own

- Provide free tools and resources for the public
- Certification courses for professionals
- Profits reinvested in research and development
- This model will promote scalability and sustainability



Early is the key...

- *Catching up* is very difficult for children on low reading and language trajectories once they get to school.
- The best solution is to help families early to support development in meaningful, everyday activities, so children are ready to learn when they enter preschool.



We have a critical window of opportunity to dramatically change the trajectory for our children in the first 3 years of life.



Engaging Families of Children with Developmental Disabilities in Early Detection, Early Intervention, and Prevention



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