HEALTHY MOTHERS, HEALTHY BABIES
Coalition of Georgia

Annual Meeting & Conference

Gwinnett Technical College

October 4, 2016

Our mission is to improve access to healthcare for Georgia's women and children through advocacy, education and access to vital resources.

HEALTHY MOTHERS, HEALTHY BABIES

Coalition of Georgia

Est. 1973

Marcus AUTISM CENTER
NIH Autism Center of Excellence

Children's Healthcare of Atlanta

EMORY UNIVERSITY SCHOOL OF MEDICINE

Early Screening, Detection, and Intervention for Autism Spectrum Disorders: New Frontiers of Research, Clinical Practice and Professional Training

Healthy Mothers, Healthy Babies Annual Meeting
October 4, 2016

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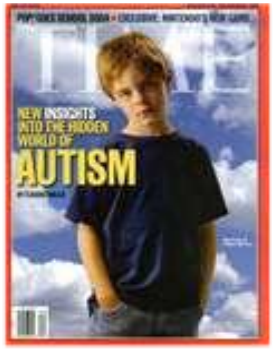
Director, Infant and Toddler Clinical Research Operations
Marcus Autism Center
Children's Healthcare of Atlanta

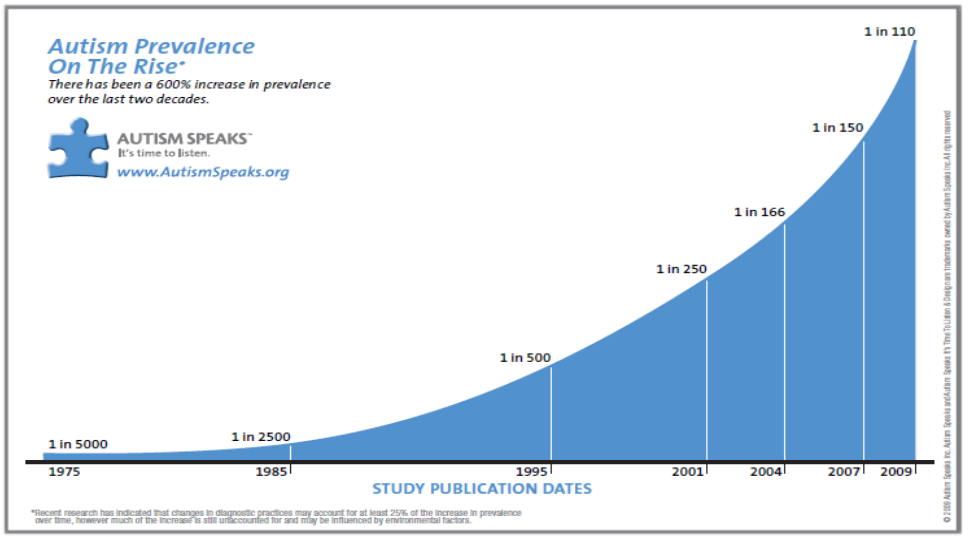
What is Autism?

DSM-5: Autism Spectrum Disorder

Delays and deviance in the development of social communication skills, with the presence of restricted and/or repetitive behaviors, present in the early developmental period.

Autism Compared to Other Common Pediatric Diseases/Conditions





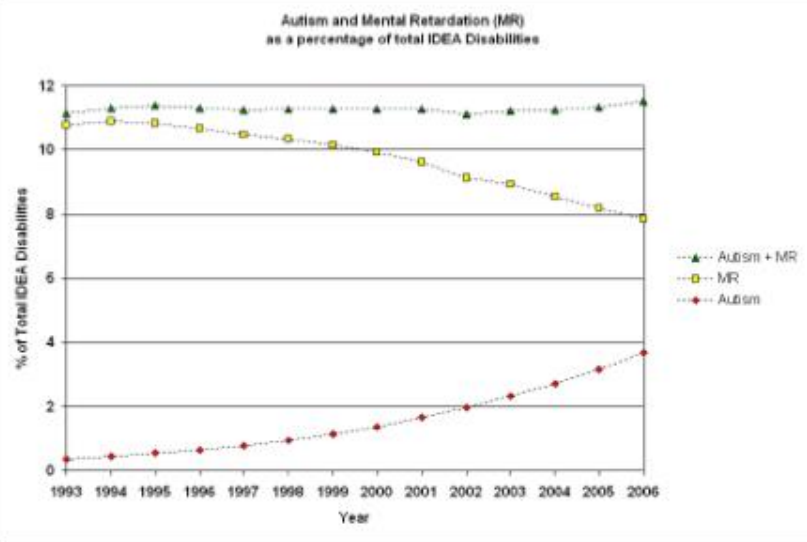
Disease/Condition	Prevalence Rate
Autism Spectrum Disorders	1:68
Congenital Heart Defects	1:125
Childhood Cancer (all types)	1:330
Juvenile Diabetes	1:500
Cystic Fibrosis	1:5,000
Muscular Dystrophy	1:20,000

For every 68 children born in the US, one of them has Autism

1 in 42 boys, 1 in 189 girls

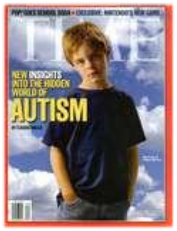
Why the Increase in Prevalence?

- Changes in diagnostic symptomatology- broadening of criteria
- Better detection at both ends of the spectrum
- Growing awareness of condition- increased media attention
- Educational implications of label
- Diagnostic Substitution



Autism and Other Developmental Delays are a Public Health Challenge

- American Academy of Pediatrics recommends screening for autism at 18 and 24 months
  - Screening (18 and 24 months), but still low uptake
  - 8% of primary care providers routinely screen for ASD
  - Studies have shown that 1/3 to 1/2 of parents of children with ASDs notice a developmental problem before their child's first birthday.
  - 80% of parents express concerns by 24 months of age.
- Despite strong genetic bases, diagnosis is behavioral, reference standards excellent (ADI-R/ADOS/expert clinician)
  - The risk of an ASD for subsequent siblings of children with ASD is 20%**; 20%; 10%
    - Majority of autism diagnoses in US outside academic medical centers
    - Usage of ADI-R and ADOS in fewer than 0.1% and 2.1%, respectively
    - Questionnaires/checklists in 30%
- Median age of diagnosis in US: 4-6 to 5.7 years
  - Later still in disadvantaged communities
- <20% of children identified before age 3 years
  - BUT Adverse outcomes can be attenuated
- No Community-viable system of care
  - Reimbursement systems NOT in place
- Importance of early diagnosis and intervention for lifelong outcome and cost of care
  - -Yet we are dependent on the currently available methods of screening, detection, diagnosis, and intervention.



Cost of Autism vs Value of Early Education: Pay Now or Pay Later

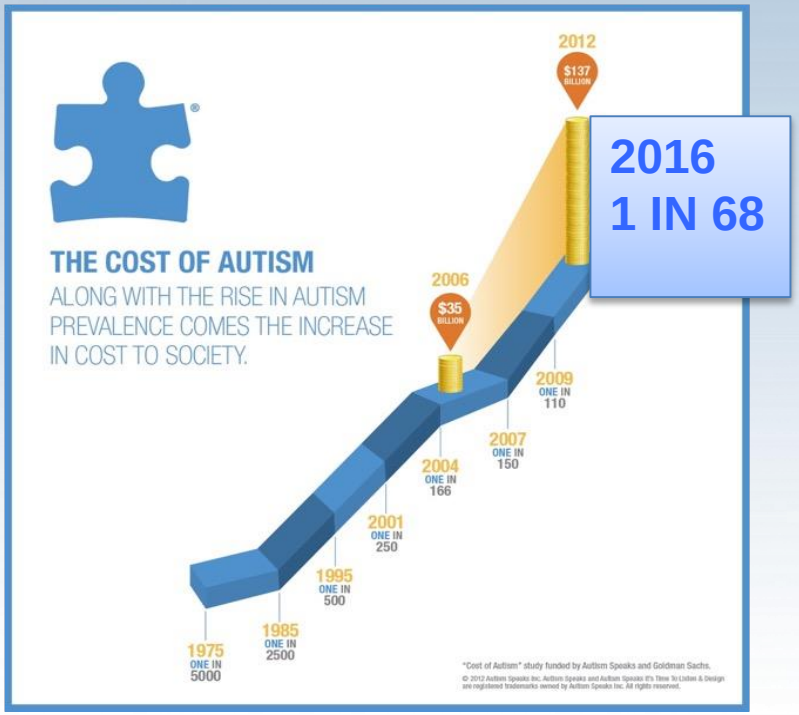
Societal Cost/Year in the US:

$136 billion

Autism is the 4th most expensive condition in the U.S. training behind trauma, cancer, and cardiovascular disease.

Lifetime Cost of Care Per Child:

$1.5- 3 million



2/3

Overall Cost

EI REDUCES the cost of lifelong care by 2/3

$12k/yr

Education Cost

Regular Education Classes approximately $12k/year less than Special Education

60%

Economic Impact

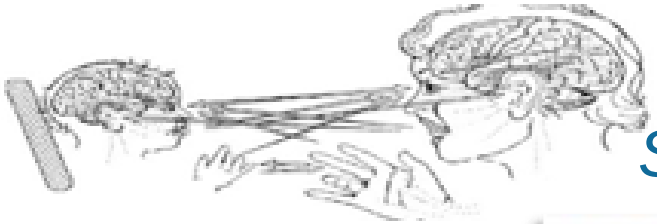
60% of the lifetime cost of autism is productivity loss for the parent & the child.

Employer Specific

- Ability to gain & retain KEY TALENT
- PRODUCTIVITY
- Healthier/More Stable Workforce

Autism Disrupts the Platform for Brain Development

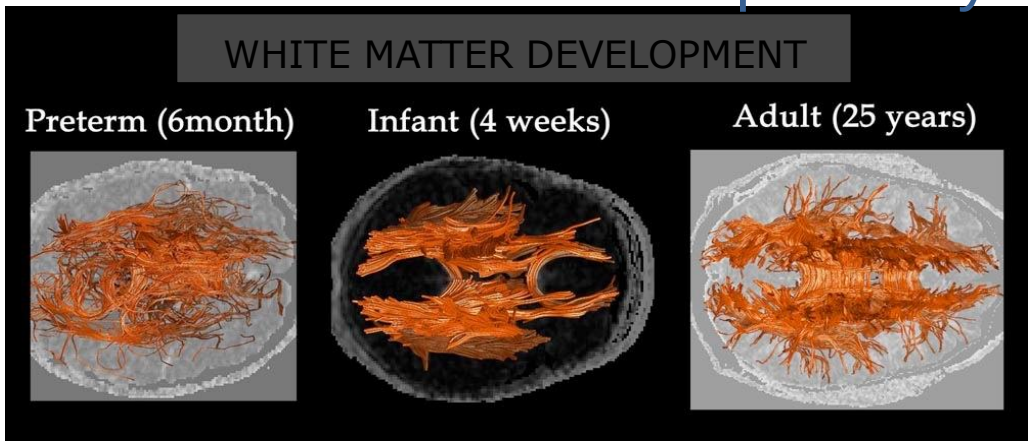
Born to Socially Orient



MH Johnson PhD

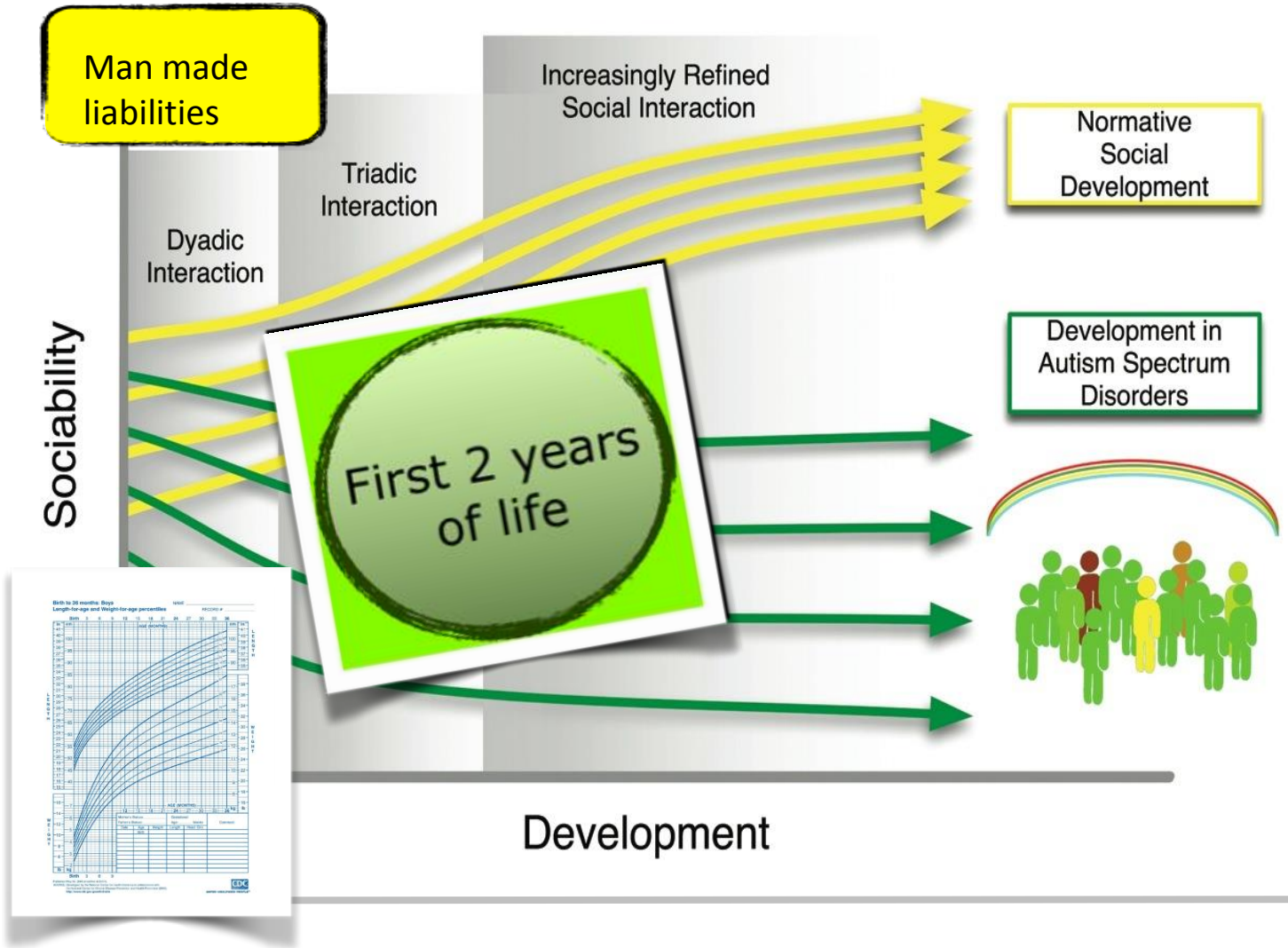
Reciprocal Social Interaction

Neuroplasticity



H-J Park PhD

GENETIC MECHANISMS OF SOCIALIZATION
BEHAVIORAL LIABILITY
SYMPTOMS



Developing expertise about the social world

Developing expertise about the psychical world

No Genetic Determinism

No Environmental Determinism

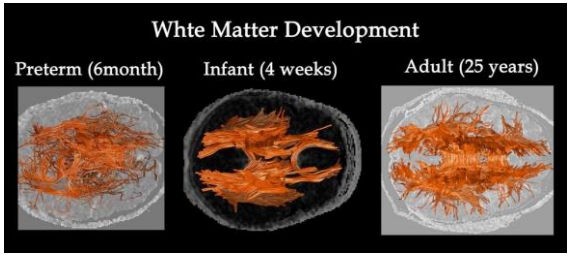
No Brain Determinism

Jones et al. (2008). *Arch Gen Psy*, 65(8), 946-54; Klin et al. (2009). *Nature*, 459, 257-61; Jones & Klin (2009). *J Am Acad of Child Psy, 48(5): 471-3; Jones & Klin (2013). Nature*, 504, 427-431*; Klin et al. (2014). Neurosci Biobehav Rev.*

Two Major Priorities in the Field

Reducing the age of diagnosis
Early diagnosis means early treatment

Improving access to early treatment
Early treatments means impacting brain growth during critical windows of development



Hae-Jeong Park, PhD

Marcus Autism Center at a Glance

Marcus AUTISM CENTER

NIH Autism Center of Excellence

Children's Healthcare of Atlanta

EMORY UNIVERSITY SCHOOL OF MEDICINE

- >5,700 unique patients/yr
- Tx: set protocols (x visits)
- > 65% on Medicaid
- ~ 40% minorities/under-served

CLINICAL OPERATIONS

- Clinical Assessment/Diagnosis
- Treatment Programs
- Center/Home/School/Community
- Care Coordination Program
- Educational Outreach Program

- Translation
- Impact
- Clinical Resources

Marcus AUTISM CENTER

NIH Autism Center of Excellence

- Science
- Faculty Advancement
- Research Resources

Excellence

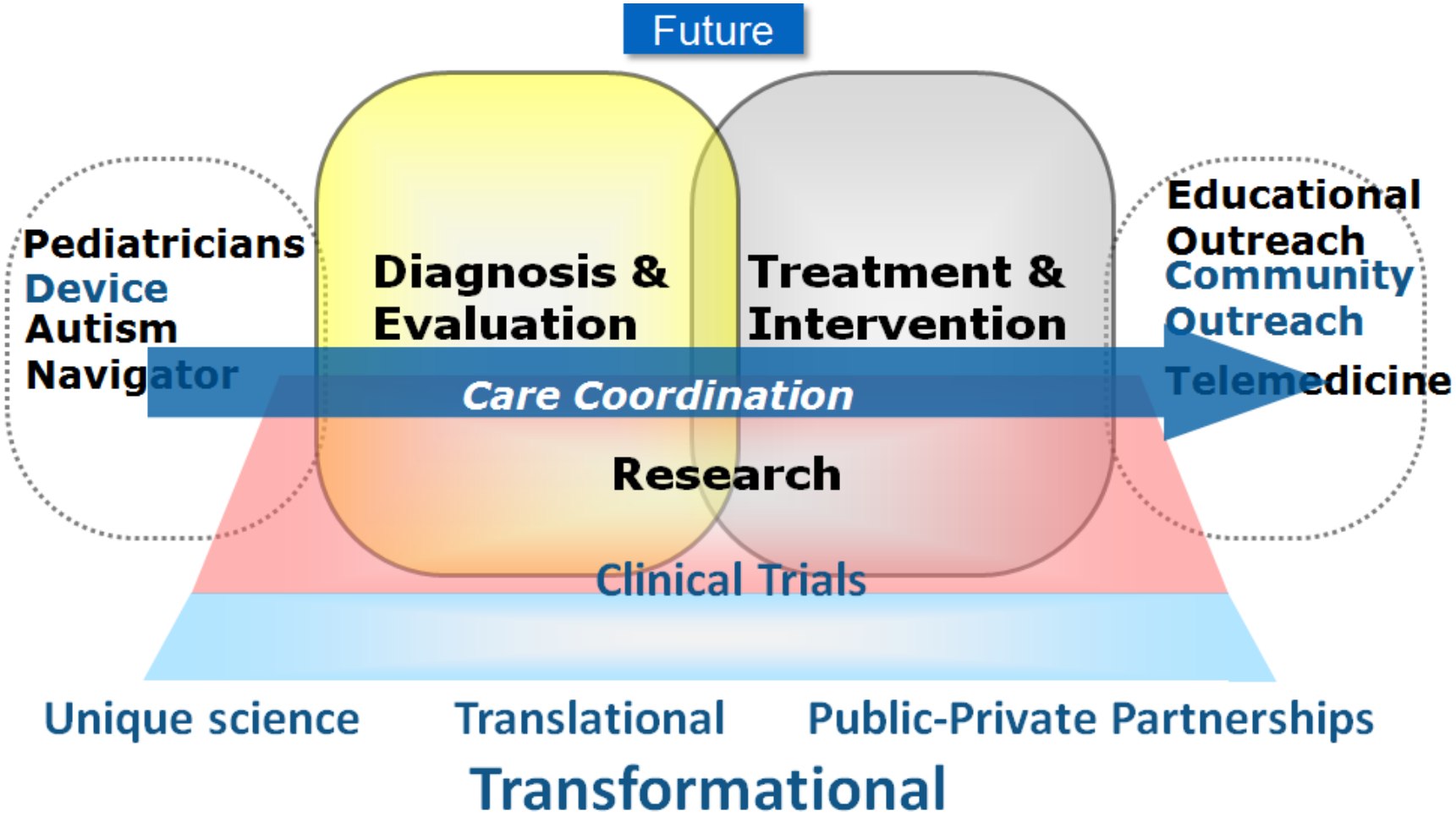
RESEARCH INITIATIVES

- CAUSES
- TREATMENT
- COMMUNITY-VIABLE SOLUTIONS
- IMPLEMENTATION SCIENCE

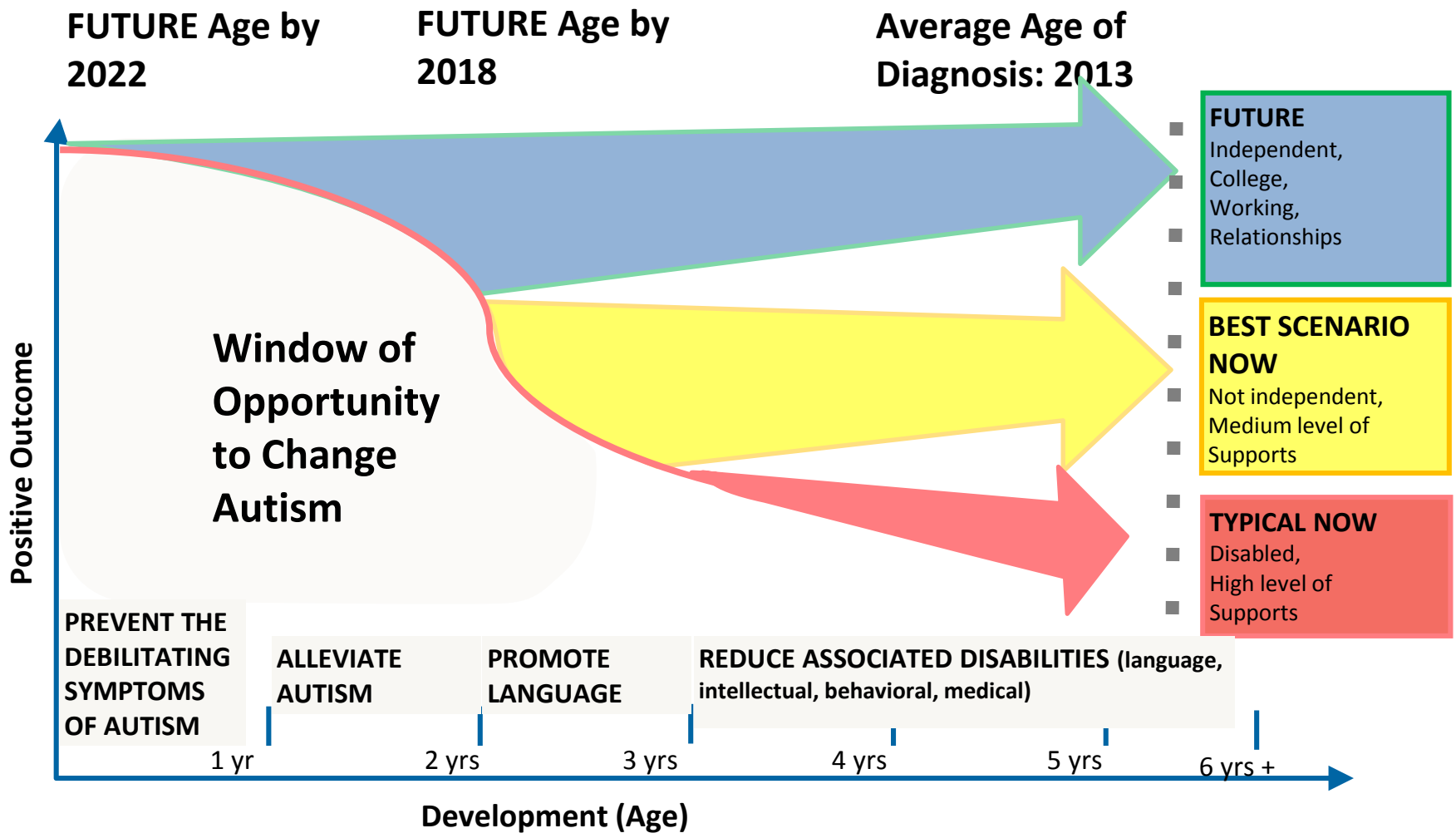
COMMUNITY-VIABLE OUTREACH MODEL

The Science of Clinical Care

Vision: Maximize the Potential of Children Today…



Vision…Change the Nature of Autism for Children of Tomorrow



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The Neurology of Social Competence

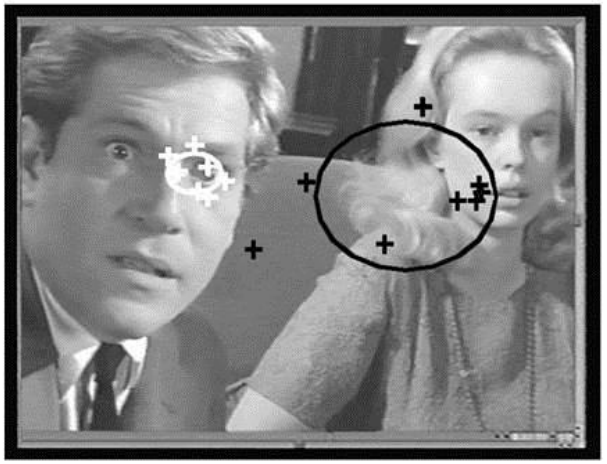
- When neurotypical infants look at peoples' faces, regions in the limbic system "light up" with endorphins and reward that child.
- By 6 months of age, a child begins to follow gaze and can recognize when they have lost the caregiver's attention.
- By 10 months of age, a child begins to shift gaze from a caregiver to objects of reference to predict and anticipate the actions of others.
- By 12 months of age, a child will initiate shared attention on desired items or items that are of interest to the child.
- These capacities foster expertise about the social world.

The Neurology of Social Competence

- These capacities ensure that a neurotypical child:
  - is drawn toward social vs. non-social stimuli
  - derives pleasure from this engagement
  - notices attention shifts of others
  - initiates bids for engagement, actions, and objects of interest
  - develops language about people and intentions to share these messages
  - engages in interactions using expected social behaviors (e.g., adhering to social norms) in order to maintain relationships over time

Unique Neurological Differences in ASD

- Children with ASD:
  - Show limited neural sensitivity to social stimuli and tend not to look toward people's faces.
  - Tend to look at the mouths of the speaker.
  - Miss gaze shifts between people and objects.
  - Have difficulty predicting actions and initiating bids for engagement.



Unique Neurological Differences in ASD

- Similarly, when neurotypical children hear speech sounds, these are processed as social or intentional stimuli. Children with ASD simply hear sounds, making the intentions of individual words more ambiguous.

- Individuals with ASD tend to process social stimuli (e.g. faces, speech sounds) in regions of the brain typically reserved to process images and sounds that are non-biological.

- This makes predictions of actions, intentions, and emotions less efficient and more intellectual.

Infants At-Risk for ASD

- Lack of, or attenuated joint attention skills
- Less interest in interactive games
- Less imitation
- Infrequency in looking at objects held by others
- Aversion to touch
- Decreased flexibility in play
- Decreased variety of toy choices and play themes
- Less appropriate play with objects
- Atypical patterns of social orienting
- Lower frequency of looking at others
- Contentedness when alone
- Poor response to name
- Reduced verbalizations/cooing
- Reduced use of gestures
- Disrupted affect regulation
- Reduced affective expressions
- Less affection toward familiar people and/or Increased negative affect

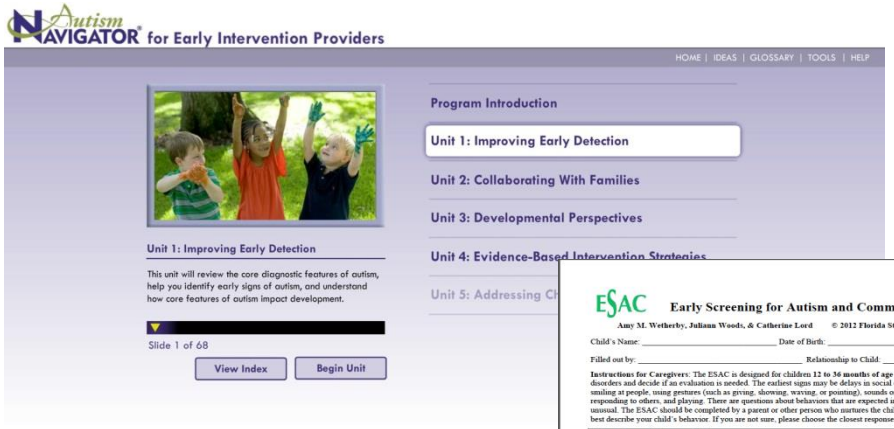
Toddlers At-Risk for ASD

- Abnormalities in social relatedness…
  - abnormal eye contact
  - limited social smile
  - limited interest in other children
  - poor response to name

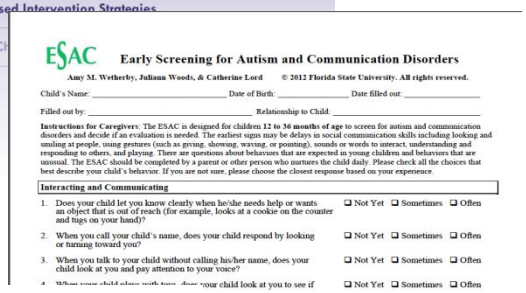
- Limited competence with social communication…
  - difficulty understanding communicative gestures from others
  - difficulty using gestures
  - decreased desire to share interests through pointing, giving and showing
  - the child may use others as a “tool”
  - A low frequency of verbal or nonverbal communication
  - Atypical affect regulation such as limited sharing of affect or a range of facial expression
  - Unusual vocalizations, body movements and sensory behaviors
  - Limited functional play, an absence of pretend play and repetitive interests/play

Emerging Methods to Facilitate Early Screening, Detection, and Intervention

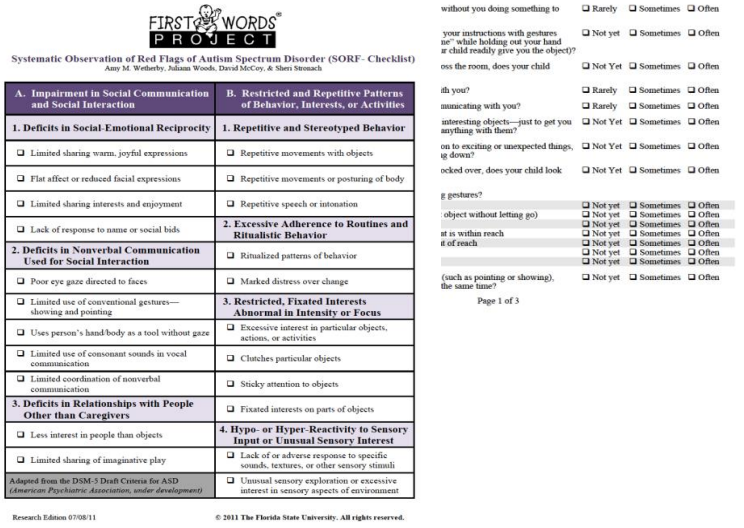
- Autism Navigator



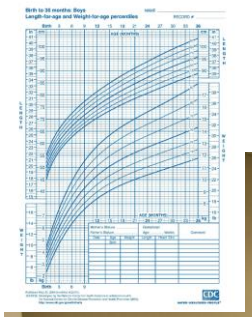
- ESAC/Smart ESAC

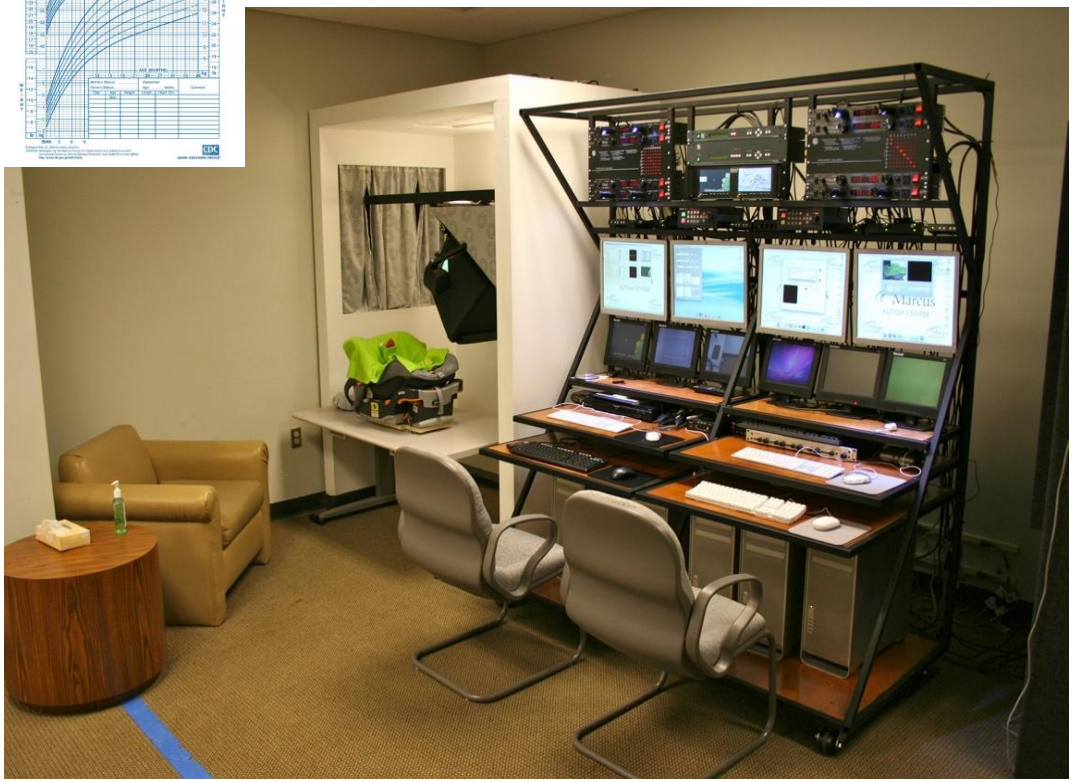


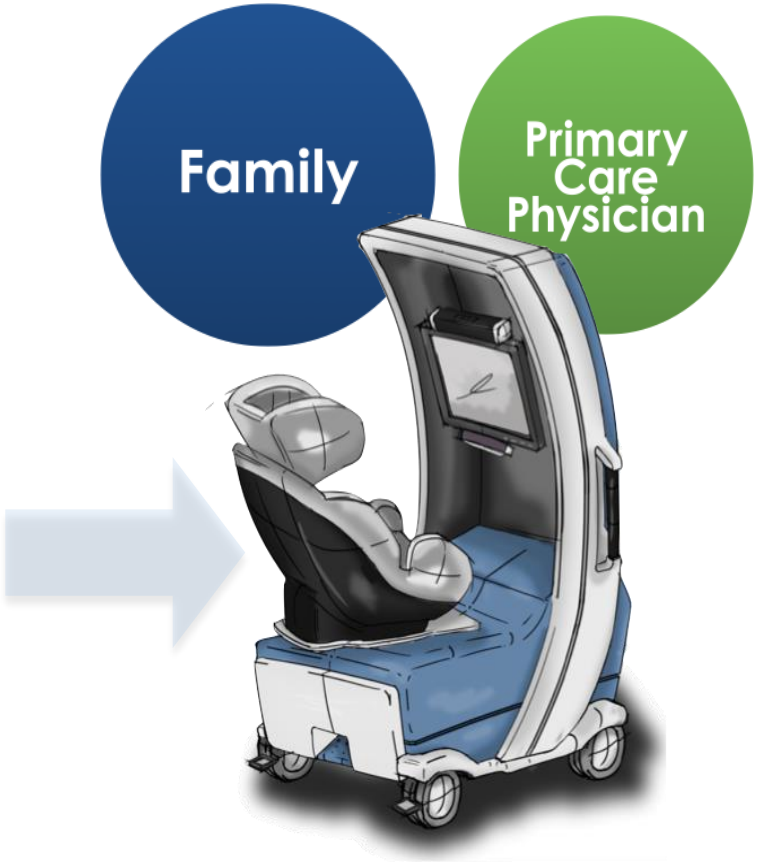
- Clinical Skill/Judgment-SORF



Eye Tracking Technology

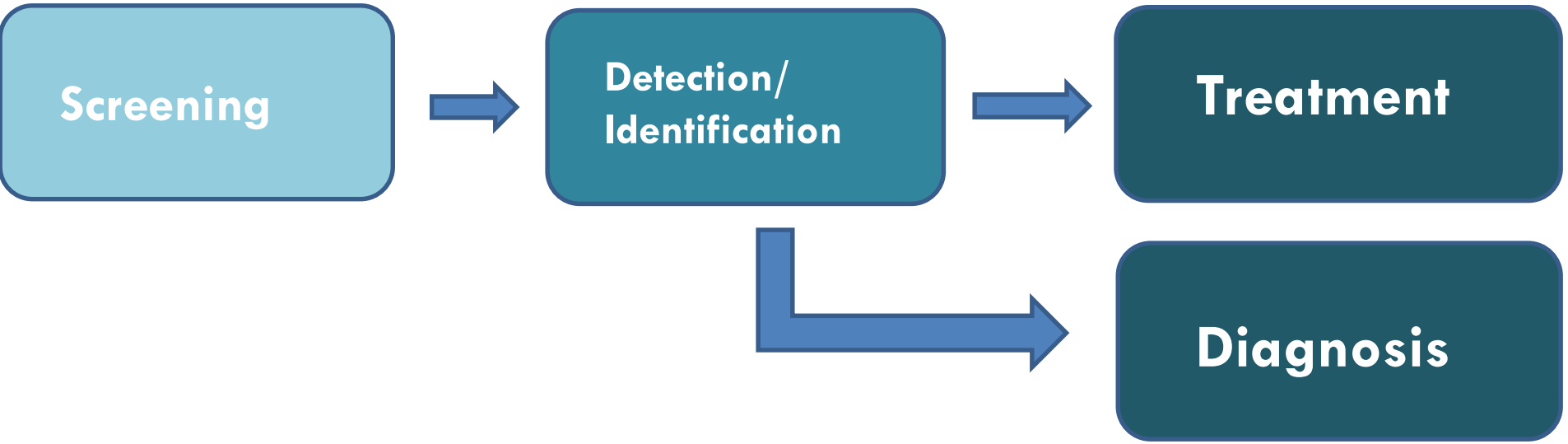






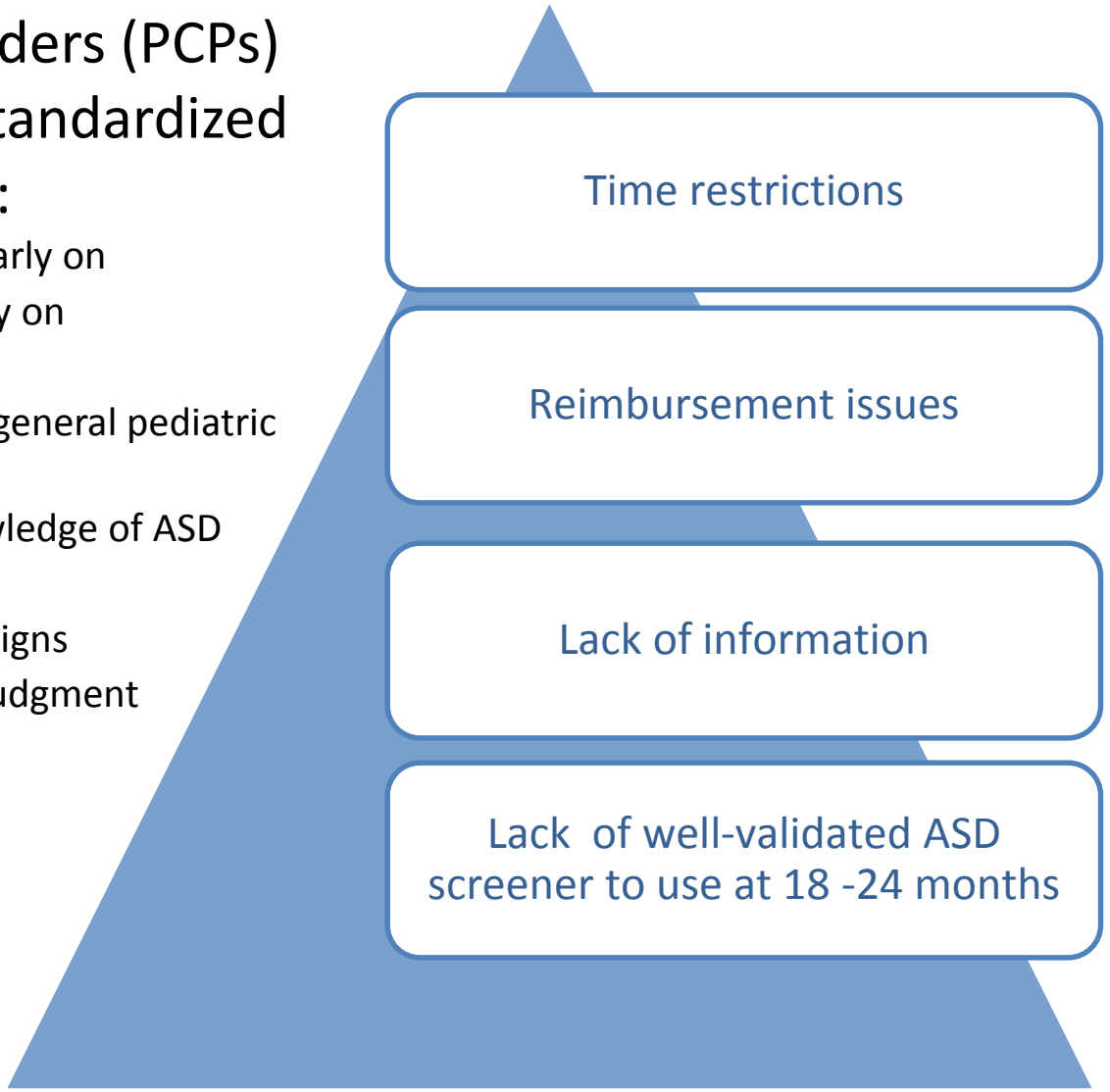
Marcus Autism Center

Access to diagnosis should not prohibit intervention for red flags.



Barriers to Early Screening and Detection

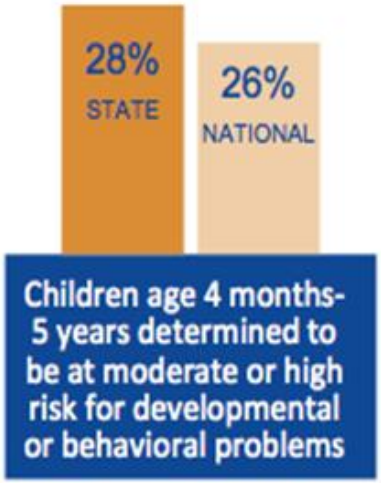
- Many Primary Care Providers (PCPs) do not conduct regular standardized screening for ASD due to:
  - Subtle symptom-expression early on
  - Diagnostic differentiation early on
  - Stability of diagnosis
  - Uptake of ASD screening into general pediatric practice remains limited
  - Dependence on clinician knowledge of ASD
  - Use of available methods
  - Recognition of early warning signs
  - Willingness to act on clinical judgment



Barriers to Diagnosis for ASD

Barriers to Early Intervention

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



Only 2% of infants and toddlers in Georgia receive Part C Early Intervention Services

<u>80% of children who need early intervention are missed.</u>

(CDC, 2009; Filipek, Accardo, Baranek et al., 1999; NRC, 2001; USDOE, 2011)

Barriers (and Opportunities) to Early Screening and Detection

- 61% of children under the age of five are in regular childcare, with the remaining percentage of children primarily being care for at home by parents or caregivers.
- Therefore, **parents and childcare providers** are the most community viable agents of change at the front line of both detecting and providing appropriate supports and services for young children at risk for ASD.

(U.S. Department of Health and Human Services, U.S. Department of Education, 2014)

The Importance of Early Intervention

- There has been mounting evidence demonstrating the effectiveness of intensive early intervention using a range of behavioral and naturalistic approaches with a substantial proportion of young children with autism spectrum disorder (ASD; Dawson & Osterling,1997).

Intervention Approaches for Infants and Toddlers at Risk for ASD

- Should focus on addressing the core impairments/challenges of children with ASD, because improvement in these areas predicts later cognitive, social, and language outcomes in children with ASD.
- Skills targeted across these core areas should include:
  - Expanding the use of gestures
  - Initiating verbal and nonverbal communication
  - Understand and using words with referential meaning
  - Initiation and responding to joint attention
  - Demonstrating reciprocity in interaction

(Woods, et. al, 2012)

Early Intervention: Challenges in Implementation

ALLEVIATE AUTISM

(National Research Council, 2001)

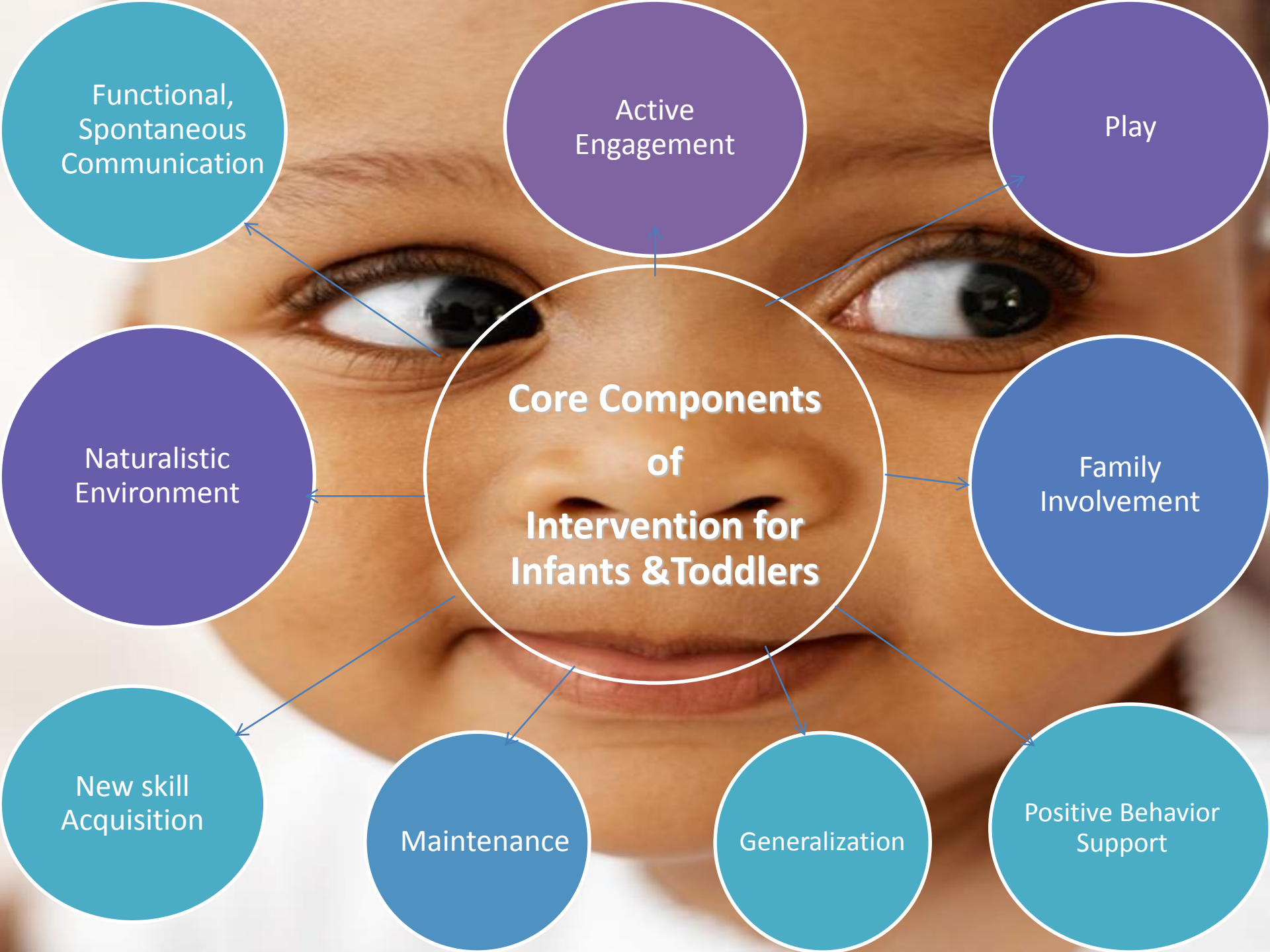
"Less than 20% of children who will need special services in school in the US are identified before the age of 3 years"

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

Naturalistic Developmental Behavioral Interventions (NDBIs)

- Implemented in natural settings
- Involve shared control between child and therapist/caregiver
- Utilize natural contingencies
- Utilize a variety of behavioral strategies to teach developmentally appropriate and prerequisite skills

(Schriebman et al., 2015)


Functional, Spontaneous Communication
Active Engagement
Play
Naturalistic Environment
Core Components of Intervention for Infants &Toddlers
Family Involvement
New skill Acquisition
Maintenance
Generalization
Positive Behavior Support

Everyday Activities

Children with ASD should receive **25 hours per week** of active engagement in systematically planned, developmentally appropriate educational activities.

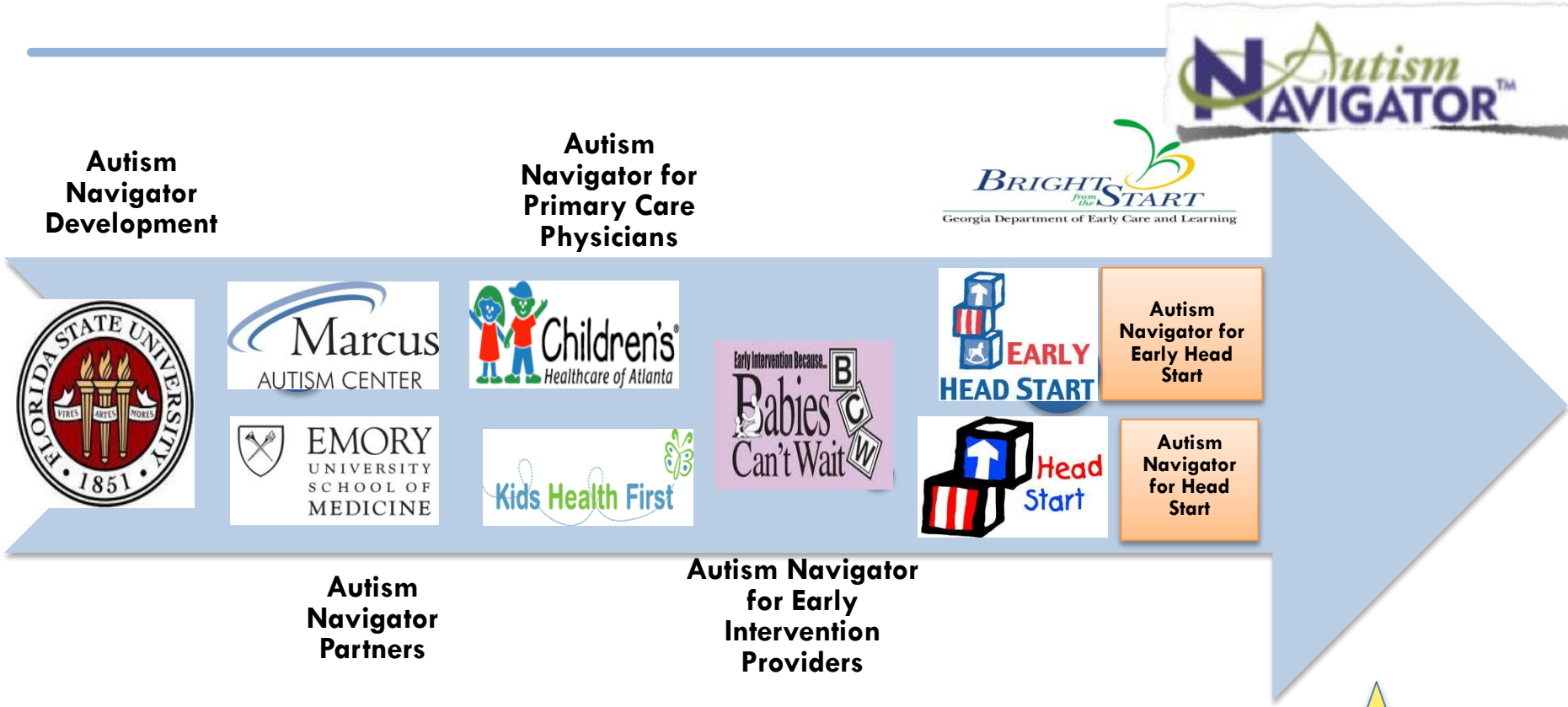
The Bridge…

- Taking highly effective interventions and creating a community viable, equal opportunity for all.
- Community viable means:
  - Cost efficient
  - Scalable
  - Maintainable
  - Accessible
  - Universal
- Community viability translates to taking the empirically validated methods and allowing them to be delivered in any community to individuals of any educational and any financial background.
- Providing evidence-based parent-implemented intervention that is commiserate with current Primary Service Provider model.

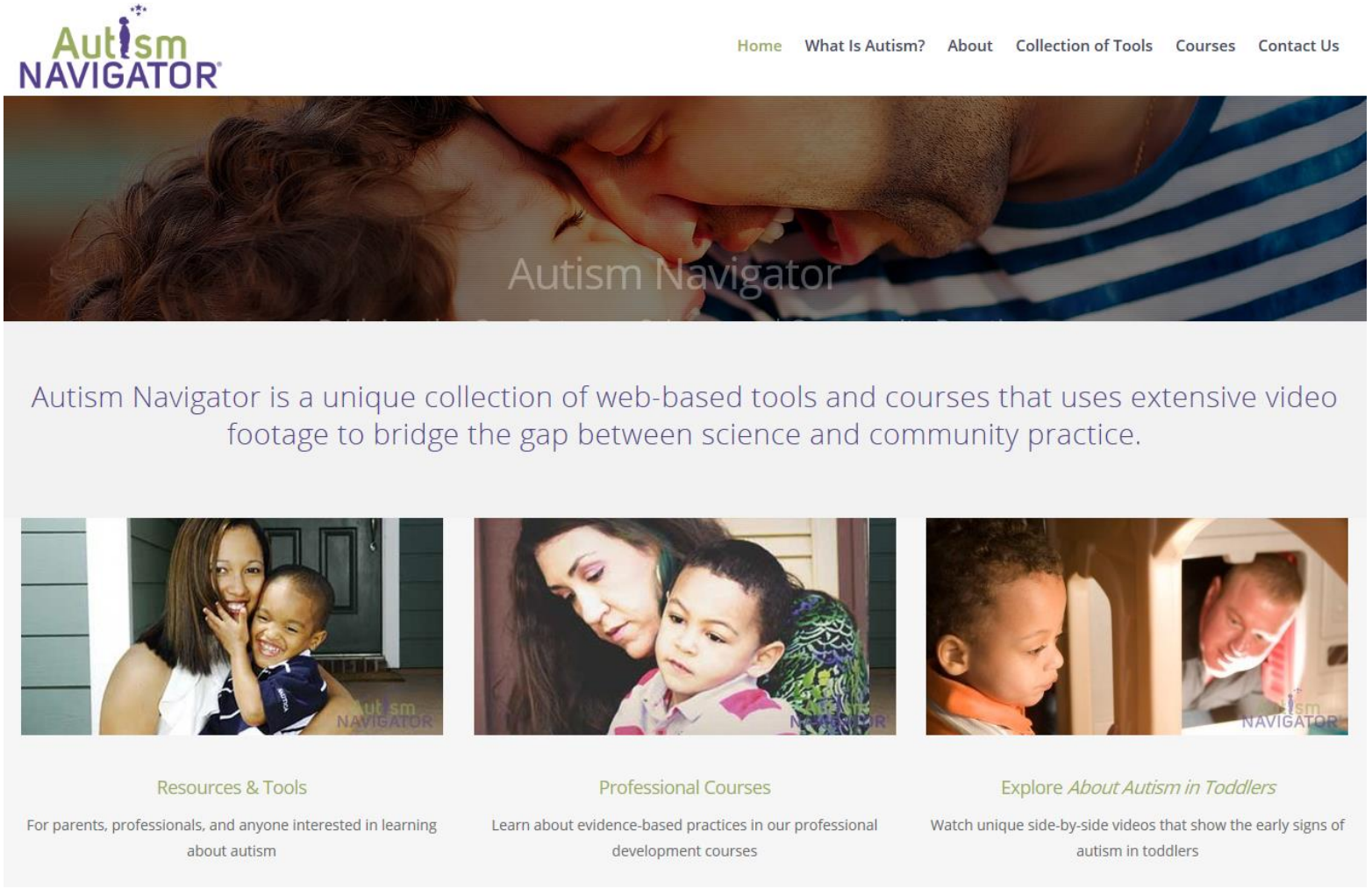
How do we continue bridging the gap between science and community practice?

So Where Do We Begin?

Training and Coaching in the Community



Bridging the Gap Between Science and Community Practice



www.autismnavigator.com

Autism Navigator

Features of the Tool:

- Highly interactive web platform
- Based on the most current research on autism
- Extensive video footage, illustrating effective evidence-based assessment and practice
- Experiential Learning Format:
  - Introduction of topic
  - Video clip
  - Commentary on the video observation
- Pre and Post Testing along with periodic information "checks" in each unit

Autism NAVIGATOR® for Primary Care

- Course Introduction
- 1. Core Diagnostic Features
- 2. Prevalence and Cause
- 3. Early Detection
- 4. Collaborating with Families
- 5. Screening & Referral
- 6. Early Intervention Basics

Recognizing Social Communication Features

Typical Development

Charlie at 16 months

Early Signs of ASD

Luke at 15 months

1 2 3

Autism NAVIGATOR® for Early Intervention Providers

- Course Introduction
- 1. Improving Early Detection
- 2. Collaborating with Families
- 3. Developmental Perspectives
- 4. Evidence-based Intervention Strategies
- 5. Addressing Challenging Behavior

From Screening to Diagnosis

Video | Commentary

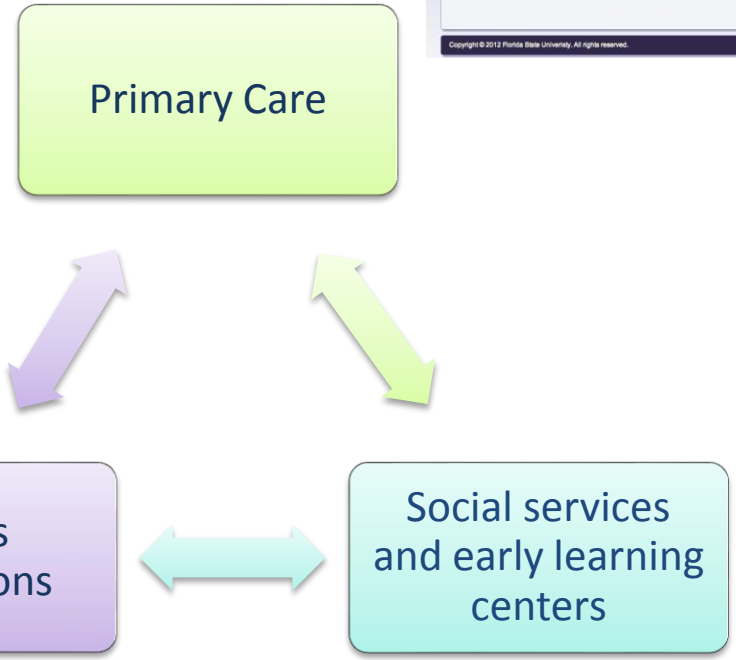
LB – 20 months

- CSBS - balloon & bubbles
- Home - washing dishes
- ADOS - bubbles
- ADOS - calling name
- ADOS - playing with truck

LB – 36 months

- Home - cooking

Mobilizing Community Systems



125 Screeners and 9,000 between 12-18 months children screened here in Atlanta! ~10% evaluated at 27 and/or 36 months

Expected Outcomes

Expected outcomes of this study include:

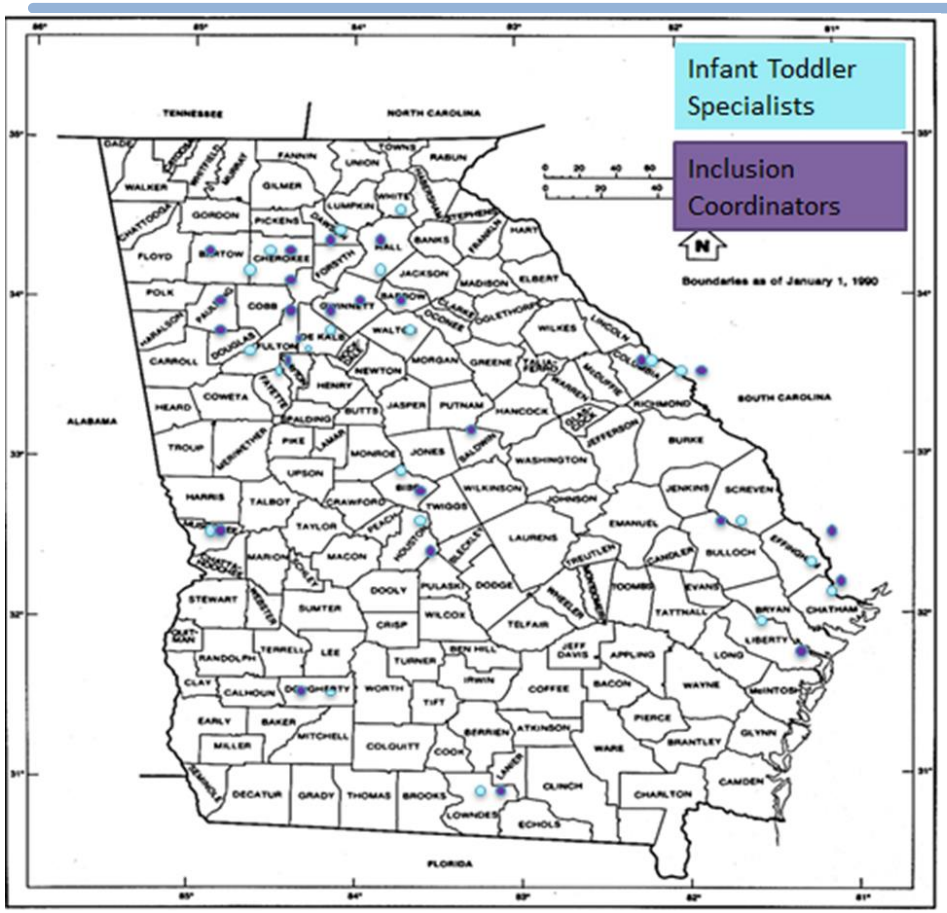
- Impacting family engagement in community screening, diagnosis, and EI.
- Demonstrating effectiveness of an integrated web-based screening system and engagement interventions.
- Contributing to identification of underserved populations through multiple community systems.
- Potentially lowering the age of identification for ASD to 18 months.

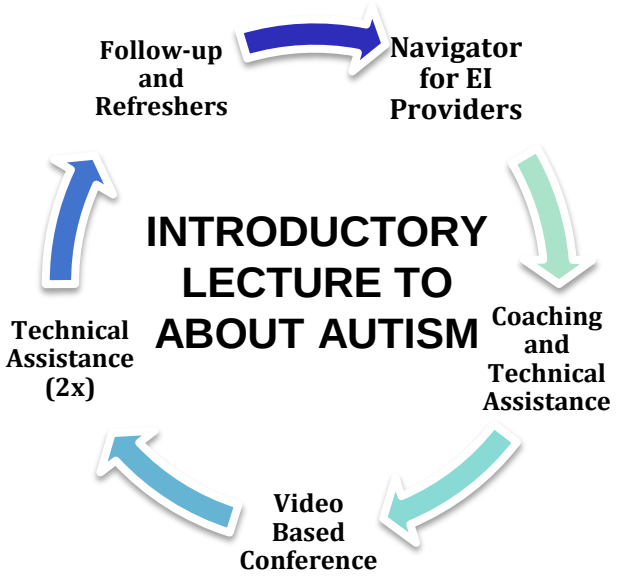
How Are We Doing So Far?

- Recruited 59 CSPS
- Screened 716 children
- 59 children have screened positive for early signs of autism
- First child comes in for no-cost diagnostic evaluation in November

- All right here in Atlanta!

Training in Early Screening, Detection, and Care for Infants and Toddlers with Red Flags for Autism

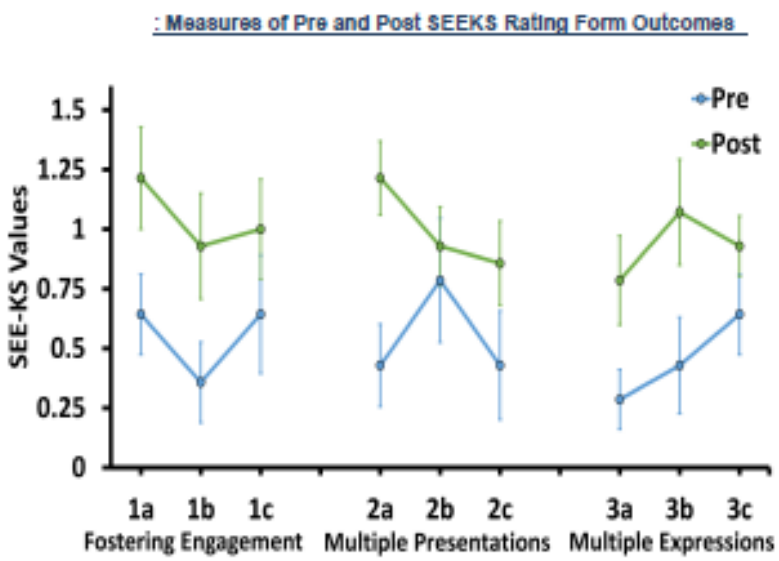


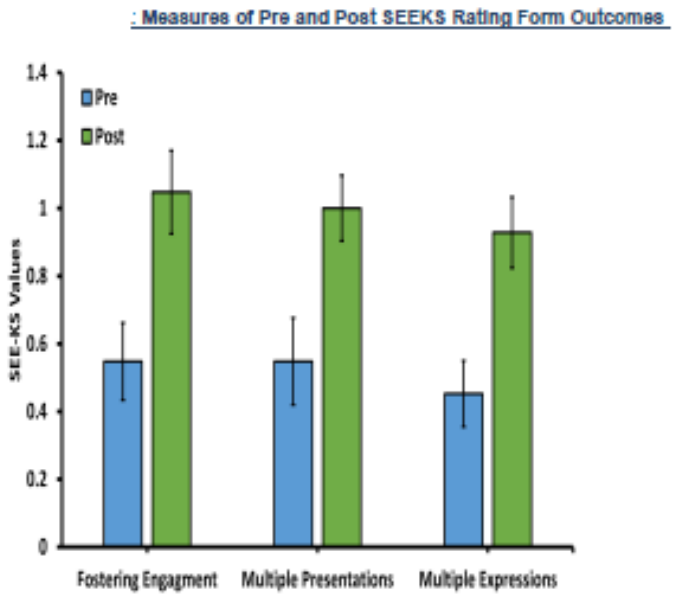


BRIGHT from the START
Georgia Department of Early Care and Learning

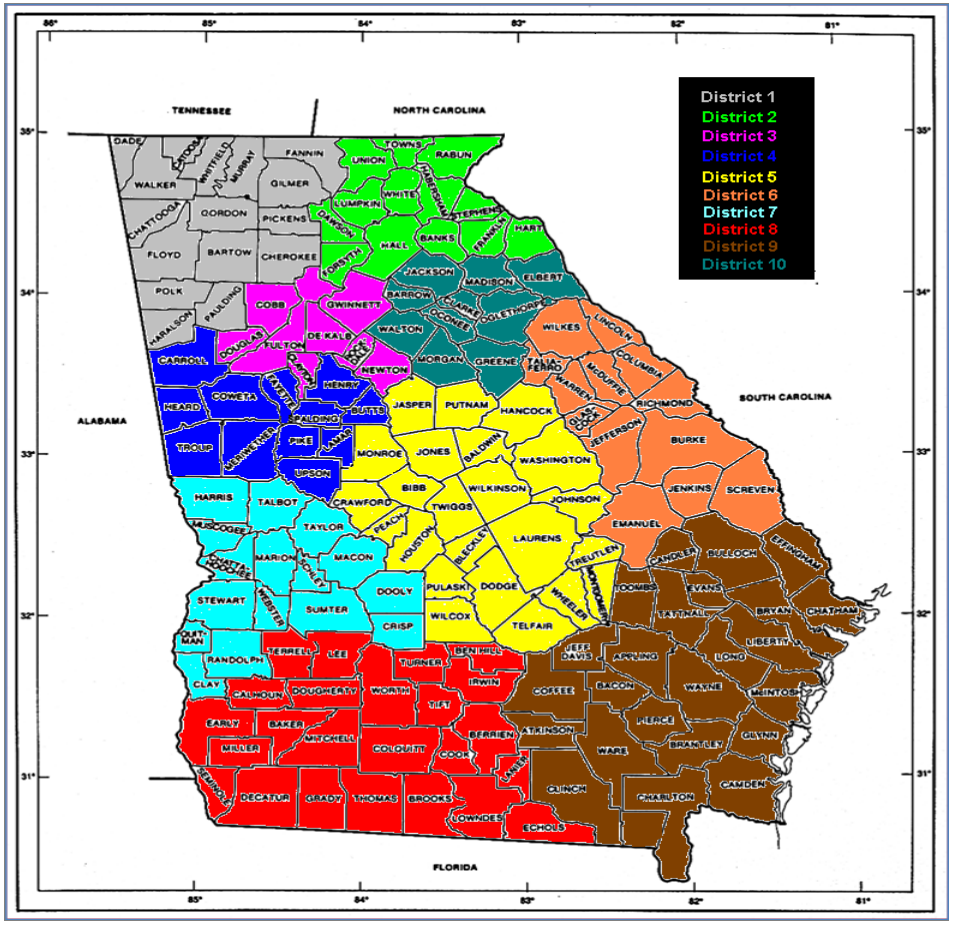
- Train mentor teacher
- Train childcare providers and teachers
- Provide parents with knowledge and milestones
- Provide community PCP tools and training

Coaching Outcomes





Training in Early Screening, Detection, and Care for Infants and Toddlers Early Intervention/Babies Can't Wait



Georgia Department of Public Health

Early Intervention Because... Babies Can't Wait

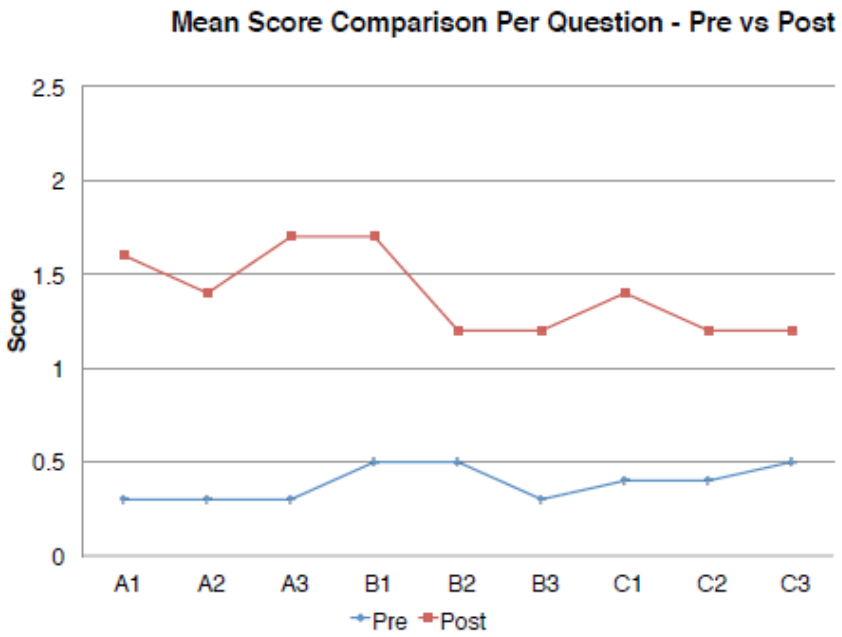
- Coaching will take place with each specialist/provider for 2 hours a week for 12 months
- Coaches will observe specialist providers with no less than 3 families
- Master coach will create an individual training plan for different families over time

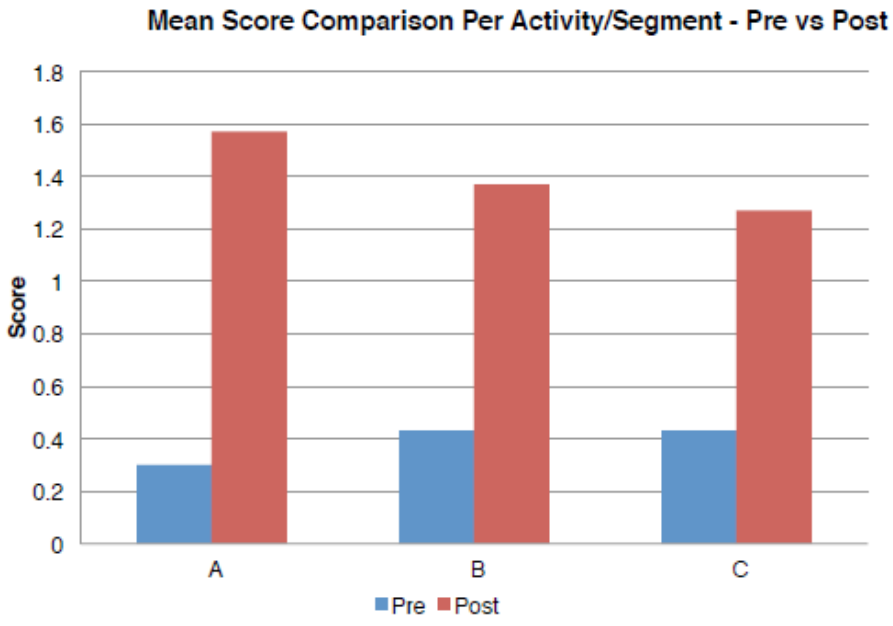
Coaching Outcomes

Descriptive Statistics on Pre/Post Scores (Per Question)

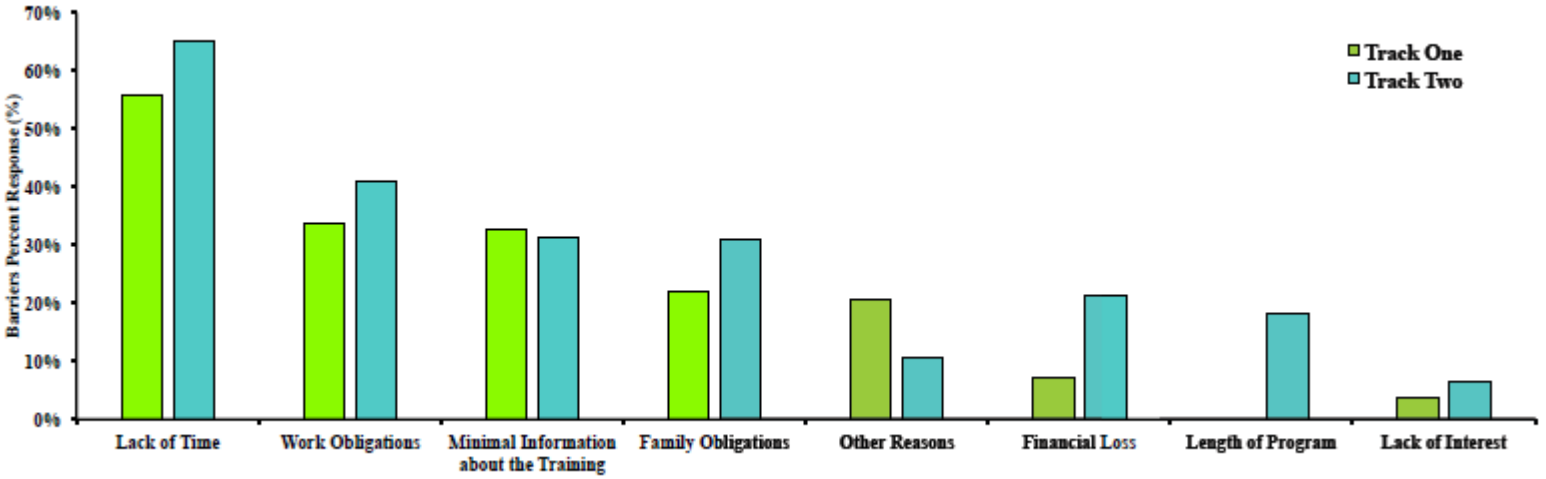
Activity/Segment	Pre Score* N=10	Post Score* N=10	p-values
A. Fostering Engagement	0.3 ± 0.11	1.57 ± 0.21	<0.001
Question 1	0.3 ± 0.14	1.60 ± 0.25	0.002
Question 2	0.3 ± 0.14	1.40 ± 0.29	0.008
Question 3	0.3 ± 0.14	1.70 ± 0.20	<0.001
B. Presenting Information in Multiple Ways	0.43 ± 0.16	1.37 ± 0.19	0.004
Question 1	0.50 ± 0.21	1.70 ± 0.14	0.001
Question 2	0.50 ± 0.21	1.20 ± 0.24	0.055
Question 3	0.3 ± 0.14	1.20 ± 0.24	0.01
C. Allowing Students to Act and Express Themselves in Multiple Ways	0.43 ± 0.13	1.27 ± 0.22	0.009
Question 1	0.40 ± 0.15	1.40 ± 0.25	0.008
Question 2	0.40 ± 0.15	1.20 ± 0.24	0.02
Question 3	0.50 ± 0.16	1.20 ± 0.24	0.036

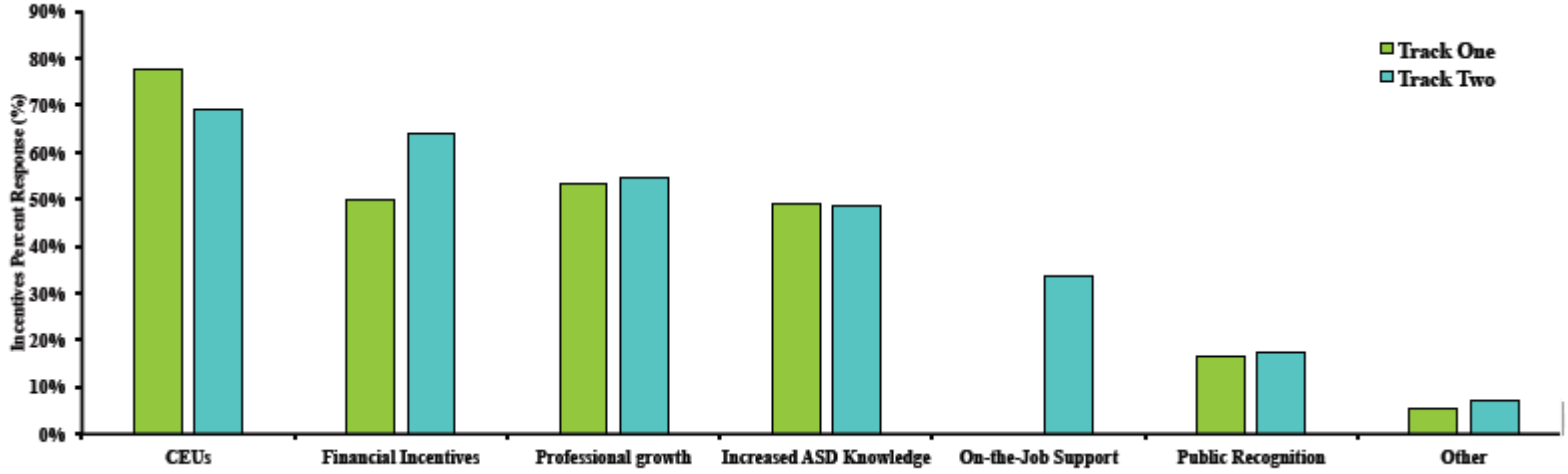
* Report in mean ± SE





Barriers and Incentives for Early Intervention



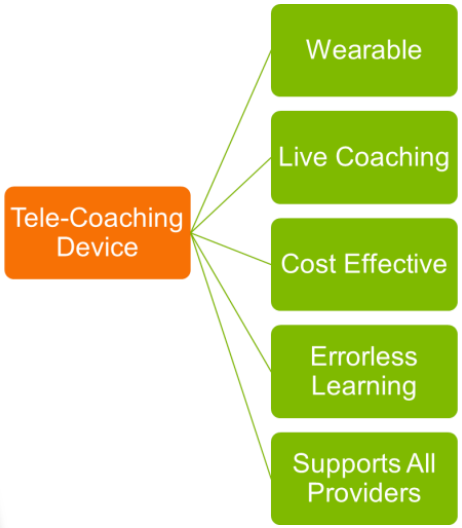


Collaborative Coaching

- Coaching is a method of transferring skills and expertise from a more experienced and knowledgeable practitioner to a less experienced one.
- Adult learning and collaboration
  - Dunst and Trivette (2012) meta-analysis study:
    - Active-learner participation
    - Multiple adult-learning strategies result in the greatest effect sizes.
    - Offer information, have multiple opportunities to practice and opportunities to evaluate and reflect on their use of strategies.

Collaborative Coaching

- Combination of in-person and mobile coaching
- Mobile coaching
  - Video review
  - Telecoaching



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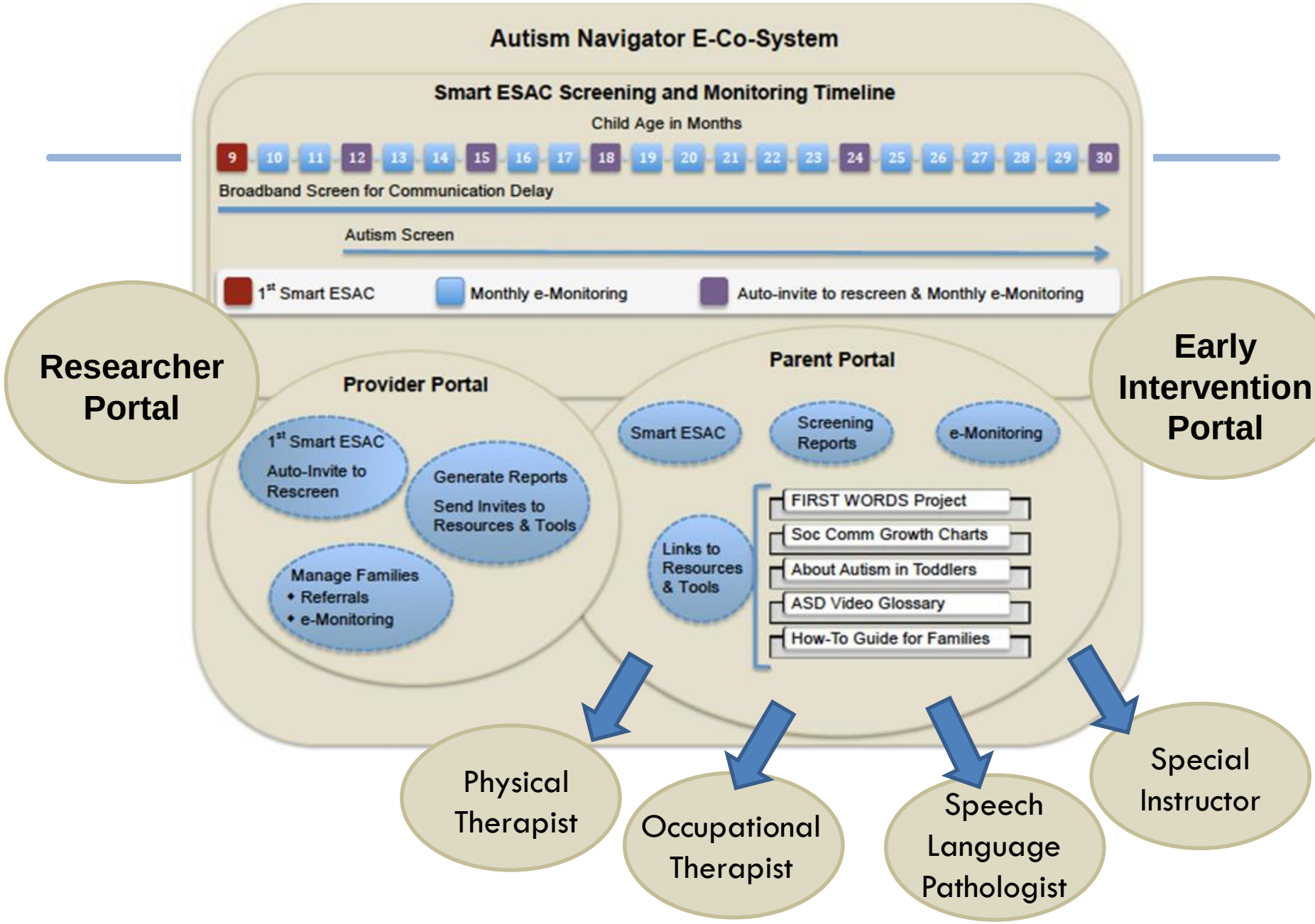
Marcus AUTISM CENTER

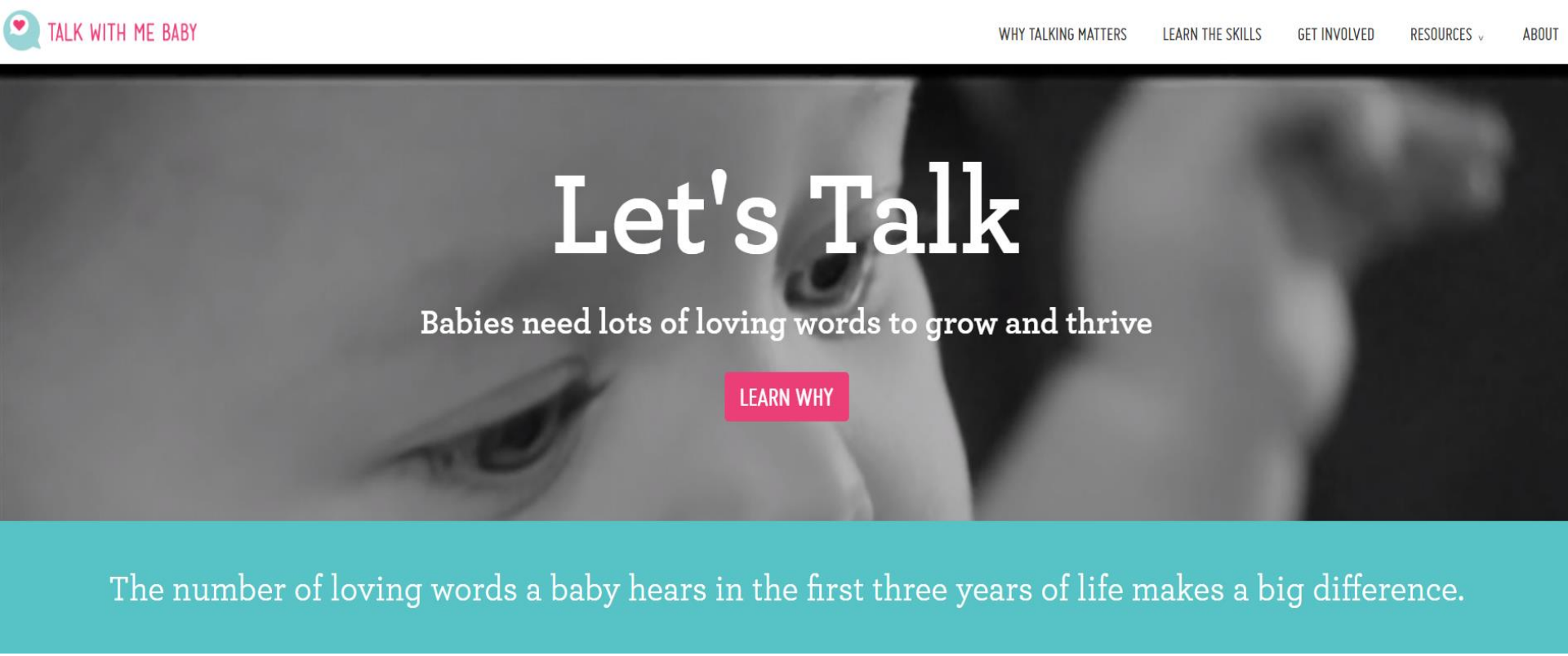
Georgia Tech

Benefits of Coaching


Autism Navigator E-Co-System
Smart ESAC Screening and Monitoring Timeline
Child Age in Months
9 10 11 12 13 14 15 16 17 18 19 20 21 22 23 24 25 26 27 28 29 30
Broadband Screen for Communication Delay
Autism Screen
1st Smart ESAC
Monthly e-Monitoring
Auto-invite to rescreen & Monthly e-Monitoring
Researcher Portal
Provider Portal
1st Smart ESAC
Auto-Invite to Rescreen
Generate Reports
Send Invites to Resources & Tools
Manage Families
• Referrals
• e-Monitoring
Parent Portal
Smart ESAC
Screening Reports
e-Monitoring
Links to Resources & Tools
FIRST WORDS Project
Soc Comm Growth Charts
About Autism in Toddlers
ASD Video Glossary
How-To Guide for Families
Early Intervention Portal
Physical Therapist
Occupational Therapist
Speech Language Pathologist
Special Instructor
The Child's Care Team

All Children, Everywhere

Language Nutrition - language that is sufficiently rich in engagement, quality, quantity and context and that nourishes the child's brain. Kids need food for growth; the also need adequate language for brain development.



The number of loving words a baby hears in the first three years of life makes a big difference.

Visit us at http://www.talkwithmebaby.org/ to learn how your words can make a big difference in your baby's life!

- Toolkit -

Leaders in other states across the country have taken note of TWMB and have shown interest in replicating the TWMB model. In response, with technical support from OSTP, and in partnership with the Barbara Bush Foundation for Family Literacy, TWMB developed an online toolkit to bring this model to scale. The toolkit makes all of TWMB's curricula, training tools, and marketing and promotional assets readily accessible.

AaBbCc

BARBARA BUSH FOUNDATION FOR FAMILY LITERACY

ABOUT

By engaging the trusted professionals who already interact with new and expectant parents, your state can ensure that all parents understand how and why to deliver Language Nutrition.

LEARN MORE

TRAINING

Talk With Me Baby prepares trusted professionals to act as Language Nutrition coaches including Nurses, WIC Nutritionists, Social Workers, Foster Parents, Early Learning Educators, and Pediatricians.

LEARN MORE

RESEARCH

The science is clear – early language exposure sets the foundation for success in school and life. Explore the research behind the Talk With Me Baby workforce engagement approach.

LEARN MORE

ENGAGING PARTNERS

The Talk With Me Baby workforce engagement approach aligns with the goals of a wide range of statewide public and private entities. Learn tips on identifying potential partners in your state.

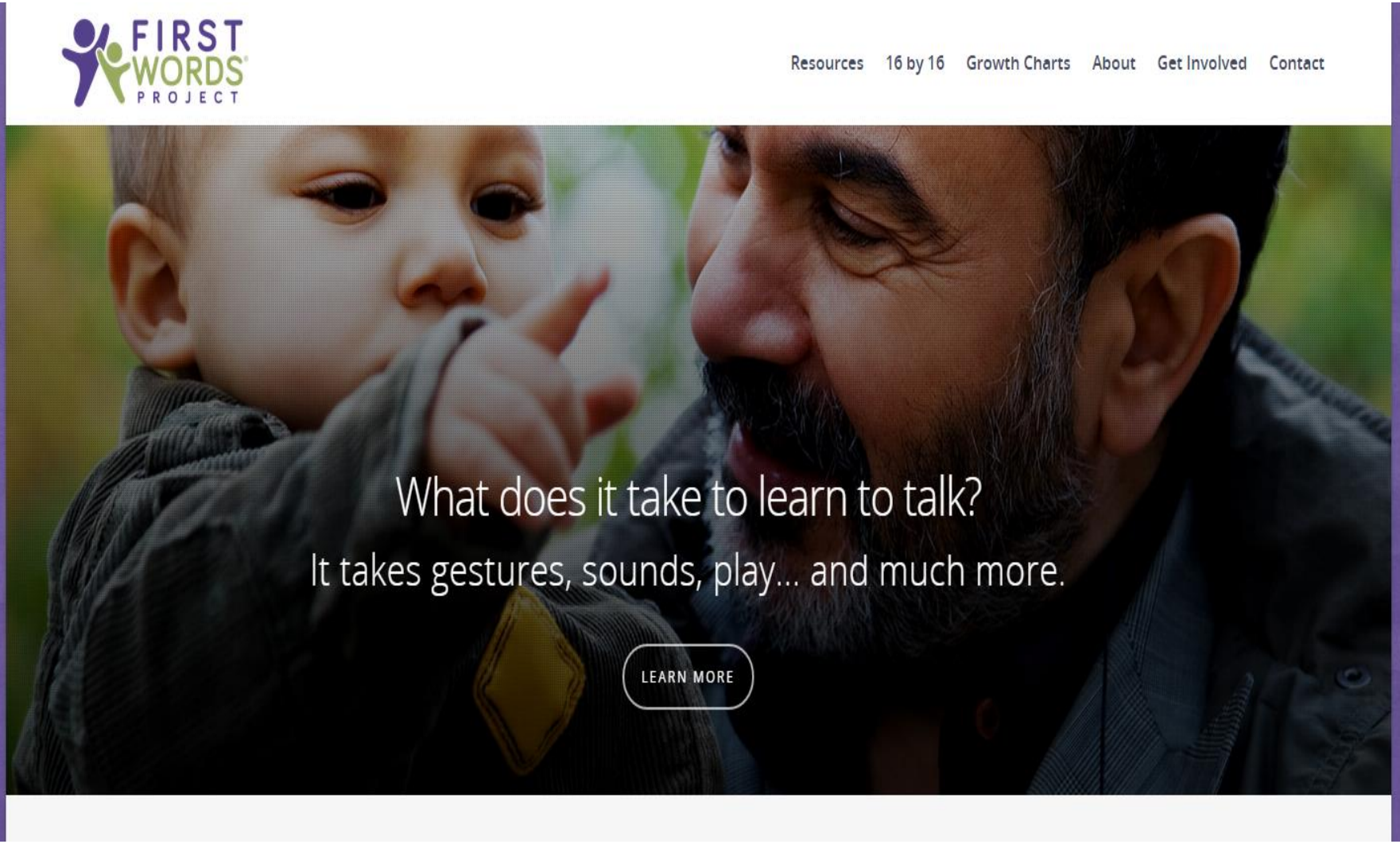
LEARN MORE

CRITICAL ELEMENTS

What does it take to "reach the people who reach the people" in promoting Language Nutrition and early brain development? Discover key components of the Talk With Me Baby approach.

LEARN MORE

http://www.talkwithmebaby.org/toolkit



firstwordsproject.com

Marcus AUTISM CENTER
NIH Autism Center of Excellence

Children's Healthcare of Atlanta

Resources

Download, print, & share these documents.

16 Gestures by 16 Months
Children Should Learn at Least
16 Gestures by 16 Months

Select a Language

Click To View

Social Communication Development
How Parents Can Support
Social Communication Development

Select a Language

Click To View

Everyday Activities
Toddlers and Their Families
Making Every Moment Count

English

Click To View

Importance of Early Intervention
This document provides details about
the importance of early intervention.

Select a Language

Click To View

Critical Information for Parents
Learn About Social Communication
Delays in Young Children

Select a Language

Click To View

What is Autism Spectrum Disorder?
This document describes ASD, how it is
diagnosed, and red flags of ASD in toddlers.

Select a Language

Click To View

Vision: Maximize Potential for Children Today; Change the Nature of Autism for Children Tomorrow

- We are making major scientific advances to detect, diagnose, and intervene earlier.
- The developmental trajectories of children at risk for autism will change appreciably and change the future for these children and their families.
- To make autism an issue of diversity, rather than disability.

Now

Future

Unique science Translational Public-Private Partnerships Transformational

Children's Healthcare of Atlanta

Thank you!
Any Questions?

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