Meeting of the Interagency Autism Coordinating Committee

Wednesday, January 17, 2018

Bethesda Marriot Hotel
5151 Pooks Hill Road
Congressional Room
Bethesda, MD 20814

Conference Call Access:
Phone: 888-928-9527
Access Code: 6435114

Meeting of the IACC

Morning Agenda

9:00 AM **Welcome, Introductions, Roll Call, and Approval of Minutes**

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive Secretary, IACC

9:10 **Advancing Behavioral Health in the Indian Health System**

Marcella Ronyak, Ph.D.
Deputy Director, Division of Behavioral Heath, HIS Headquarters, HHS

Meeting of the IACC

Morning Agenda - continued

10:00 **Summary of Advances Discussion**

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive Secretary, IACC

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

11:00 **Morning Break**

Welcome
Introductions
Roll Call
Approval of Minutes

Joshua Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC

Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination
Executive Secretary, IACC
National Institute of Mental Health

Advancing Behavioral Health in the Indian Health System

Interagency Autism Coordinating Committee

January 17, 2018

Overview of Today's Talk

- Provide an overview of the Indian Health Service System
- Discuss current behavioral health initiatives in the Indian health system to promote Native American health to the highest level
- Discuss the role and impact of telebehavioral health services to enhance service delivery

U.S. DEPARTMENT OF HEALTH & HUMAN SERVICES

INDIAN HEALTH SERVICE

OVERVIEW

MISSION

To raise the physical, mental, social, and spiritual health of American Indians and Alaska Natives to the highest level

GOAL

To ensure that comprehensive, culturally acceptable personal and public health services are available and accessible to American Indian and Alaska Native people

FOUNDATION

To uphold the Federal Government's obligation to promote healthy American Indian and Alaska Native people, communities, and cultures, and to honor and protect the inherent sovereign rights of Tribes

LEGISLATION

- Snyder Act, P.L. 37-85 (1921)
- Transfer Act, P.L. 83-568 (1955)
- Indian Health Care Improvement Act (1976 & 2010)
- Indian Sanitation Facilities Act, P.L. 86-121 (1959)
- Indian Self-Determination & Education Assistance Act, P.L. 93-638 (1975)

PRIORITIES

PEOPLE

PARTNERSHIPS

QUALITY

RESOURCES

COMPREHENSIVE HEALTH SERVICE DELIVERY SYSTEM

2.2 million — Number of American Indians and Alaska Natives eligible for services

567 — Number of Federally recognized tribes served

12 — Number of IHS Areas across the United States

HOSPITALS

26 IHS
22 Tribal

HEALTH CENTERS

53 IHS
289 Tribal

ALASKA VILLAGE CLINICS

150 Tribal

URBAN HEALTH CENTERS

34 IHS

HEALTH STATIONS

30 IHS
73 Tribal

SCHOOL HEALTH CENTERS

4 IHS
15 Tribal

FY 2017 IHS Budget

- Discretionary Budget Authority - $4.9 billion
- Special Diabetes Program for Indians - $147 million

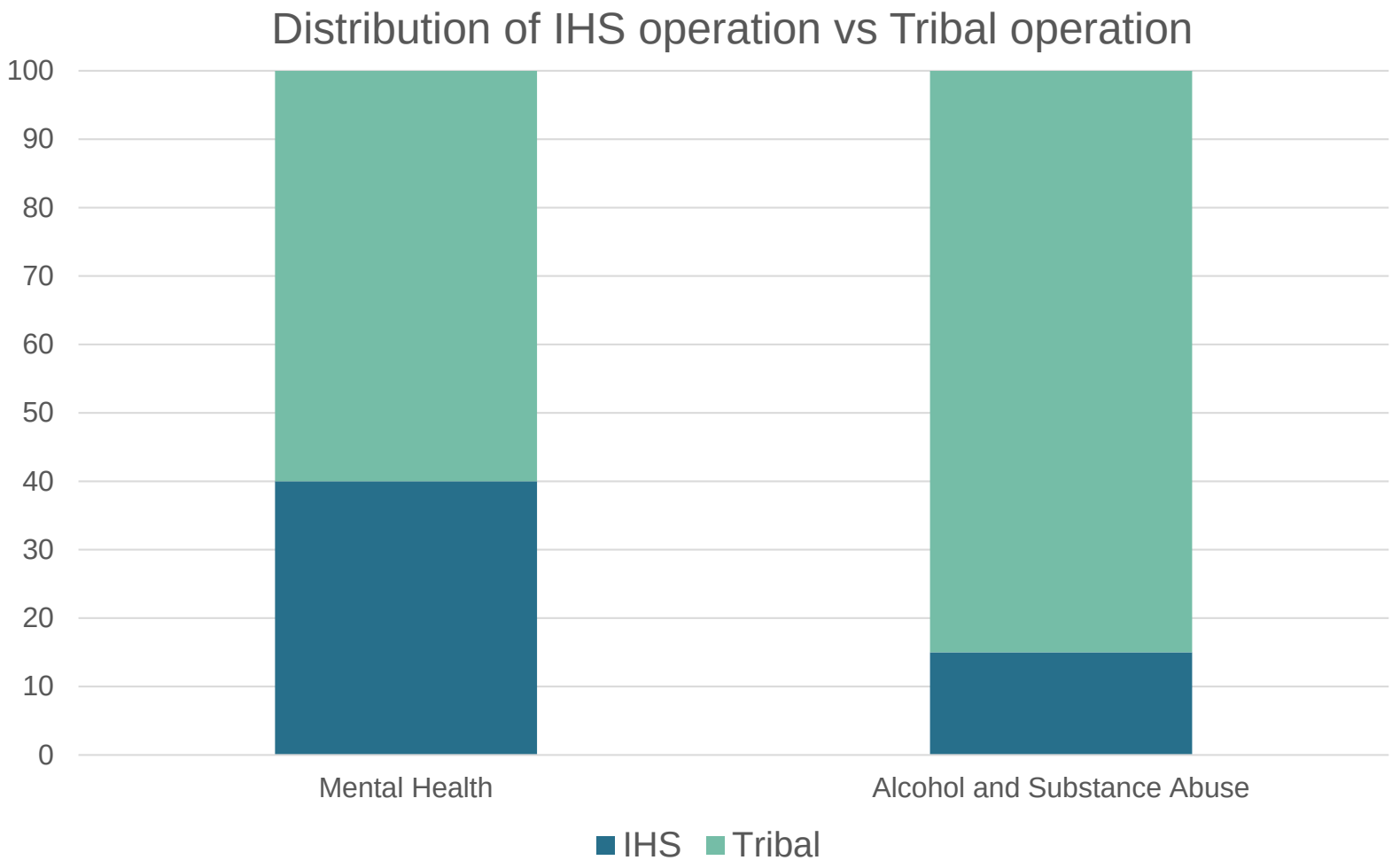
TOTAL = $5.1 billion

FY 2017 Behavioral Health (BH) Budget

- Alcohol and Substance Abuse - $218,353,000
- Mental Health - $94,080,000

TOTAL = $312.4 million

Tribal Management of BH Services



Quick Look at Indian BH System

- Approximately 2000 IHS, tribal, and urban Indian mental health and alcohol & substance abuse personnel
- 500 mental health and alcohol & substance abuse programs across AI/AN communities
- 12 Youth Regional Treatment Centers in operation with 1 more Congressionally mandated and under construction planning

Division of Behavioral Health (DBH) Major Functions

- Policy Development
- Program Planning
- Budget Formulation
- Support & Resources
- Special Initiatives
- Grant Funding

IHS Area Behavioral Health Consultants

- Represent each of the 12 IHS Areas
- Advise DBH on the needs and activities of each IHS Area
- Provide information from Service Units

Special Initiatives

- Trauma Informed Care
  - Family Spirit
  - Pediatric Integrated Care Collaborative
- Youth Focus
  - Generation Indigenous (Gen-I)
  - Children & Mental Health Services in Schools
  - Boys & Girls Clubs of America – Native Services

Boys & Girls Clubs of America – Native Services MOU

- Focuses on preventing behavioral health disparities among Native children and youth
- 11 BGCA funded through IHS

BH Grant Programs

- Substance Abuse and Suicide Prevention
- Domestic Violence Prevention
- Behavioral Health Integration Initiative
- Zero Suicide Initiative
- Urban Indian Health Education & Outreach
- Preventing Alcohol-Related Deaths
- Youth Regional Treatment Center Aftercare

Substance Abuse and Suicide Prevention (SASP)

- Established in 2009 as the Methamphetamine and Suicide Prevention Initiative (MSPI)
- Total of 175 total projects at $27.9 million
- Funding cycle runs from Sep 2015- Sep 2020

SASP Purpose Areas

- Purpose Area 1:
  - Community and Organizational Needs Assessment and Strategic Planning
- Purpose Area 2:
  - Suicide Prevention, Intervention, and Postvention
- Purpose Area 3:
  - Substance Abuse Prevention, Treatment, and Aftercare
- Purpose Area 4:
  - Generation Indigenous Initiative (Gen-I) Support

Domestic Violence Prevention (DVP)

- Established in 2010 as the Domestic Violence Prevention Initiative (DVPI)
- Total of 83 projects at $11.2 million
- Five-year funding cycle from Sep 2015-Sep 2020

DVP Purpose Areas

- Purpose Area 1: Domestic and Sexual Violence Prevention, Advocacy, and Coordinated Community Responses

- Purpose Area 2: Forensic Healthcare Services

Behavioral Health Integration Initiative (BH2I)

- $6M for 12 awards at $500,000/year for 3 years
- Funding cycle: Sep 2017 – Sep 2020
- Focuses on integrating behavioral health with primary care

Zero Suicide Initiative

- Aims to reduce the risk of suicide for all individuals seen in health care systems
- Began with ten pilot sites in Dec 2015
- Funded 8 sites to implement Zero Suicide
- $400,000/year for 3 years
- Funding cycle Nov 2017 – Nov 2020

BH Grant Programs

- **Urban Indian Health Education & Outreach:**
  - $75,000 to National Council on Urban Indian Health
  - Focuses on increasing the national awareness and visibility of behavioral health in urban Indian communities
- **Preventing Alcohol Related Deaths**
  - 2 awards
    - Oglala Sioux Tribe - $500k
    - Navajo $1.5M
  - Project started Sep 30, 2017
  - Focuses on providing social detoxification services for alcohol
- **Youth Regional Treatment Center Aftercare:**
  - $1.6M for 2 awards
    - 1 IHS YRTC
    - 1 Tribal YRTC

TeleBehavioral Health Center of Excellence (TBHCE)

- Provides Tele-Education and Telehealth Technical Assistance to all 12 IHS Areas, including IHS, Tribal, and Urban providers.
- Provides Telebehavioral Health services in 9 IHS Areas.
- Intra-Area Agreements with 8 IHS Areas that allow for telebehavioral health services throughout those Areas.

TeleBehavioral Health Sites

FY2017 TeleBehavioral Health Service Summary

- Services Provided
  - 8,101 patients seen
  - 4,051 hours of service
  - 24 IHS, Tribal, and Urban Sites
- Service Types
  - Child 31%
  - Counseling 30%
  - Addiction 21%
  - Adult 18%

FY2017 Tele-Education Summary

- 118 educational webinars
- 8,924.5 hours of training provided
- 4,336 Continuing Education hours claimed
- 4,440 Support tickets closed
- 42 webinars hosted for others
- 3 conference streaming provided
- 26 Trauma Informed Care webinars
- 10 IHS Clinical Rounds
- Launched On-Demand version of Essential Training on Pain & Addiction

Indian Children's Program (ICP)

- TBHCE provides education, training, and consultation on issues affecting American Indian/Alaska Native (AI/AN) youth such as:
  - Autism
  - Fetal Alcohol Spectrum Disorders (FASD)
  - ICP Pediatric Neuropsychology Consultation

TBHCE Pediatric Consultation Clinic

- A free provider-to-provider consultation clinic for issues such as:
  - FASD (Fetal Alcohol Spectrum Disorder)
  - ASD (Autism Spectrum Disorder)
  - ADHD (Attention Deficit/Hyperactivity Disorder)
  - Intellectual Disability
  - Learning Disorders
  - TBI (Traumatic Brain Injury)
  - General cognitive disorders
  - General behavioral problems
  - Language Disorders
  - Genetic Disorders
  - Medication management
  - *If you would like more information about the Pediatric Consultation Clinic, it can be found here (https://www.ihs.gov/telebehavioral/icp/icpfaqs/). If you would like to request a consultation, please go here (https://www.surveymonkey.com/r/3RTJYZF) . The clinic is open to all I/T/U providers.

Achieving the IHS Mission

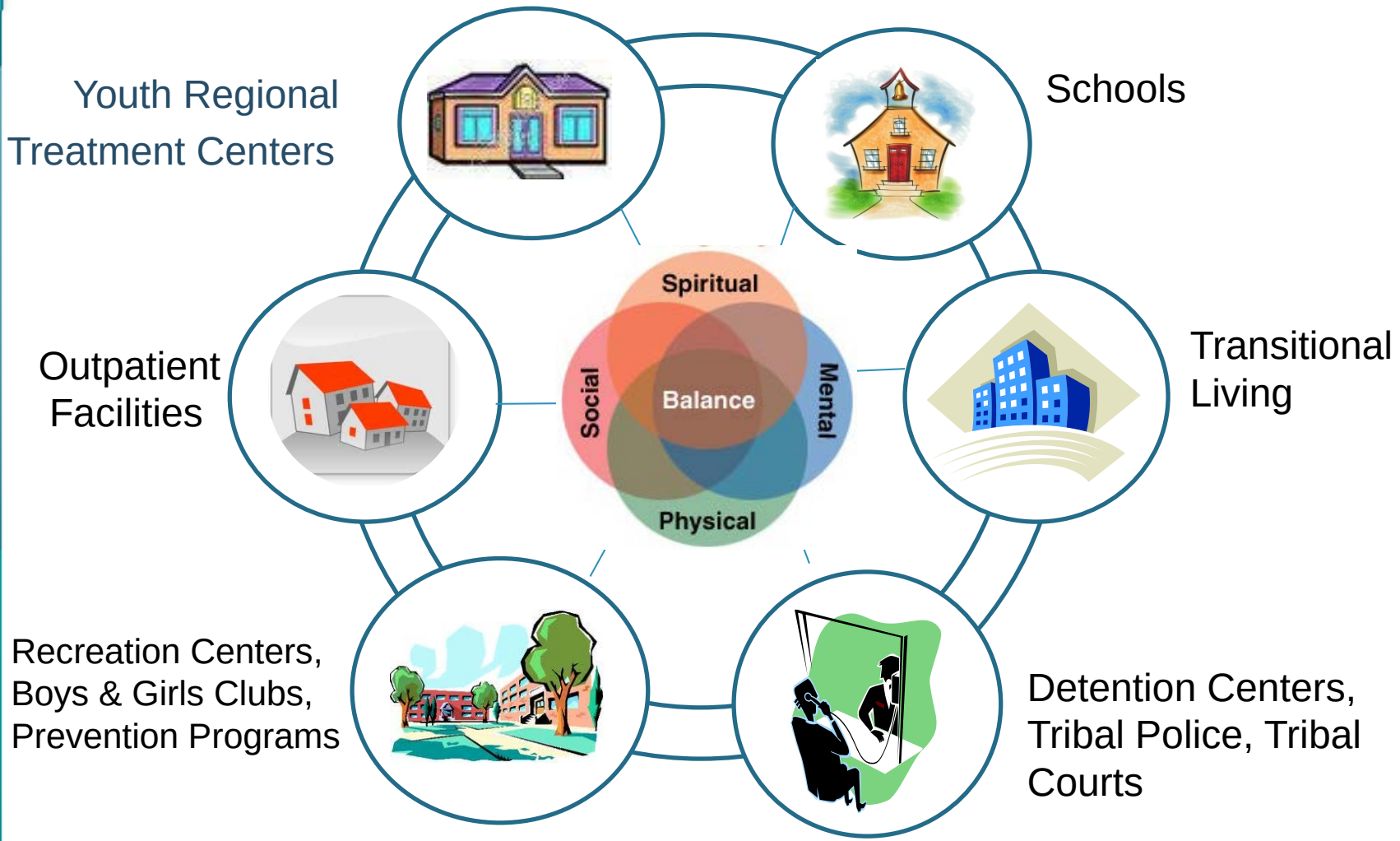


Figure 1: Coordination Model, *Adapted from materials developed by the Office of Inspector General*

STAY CONNECTED WITH THE FUTURE OF IHS

WWW.IHS.GOV

WWW.FACEBOOK.COM/IndianHealthService

WWW.YOUTUBE.COM/IHSGOV

WWW.TWITTER.COM/IHSgov

WWW.LINKEDIN.COM/COMPANY/INDIAN-HEALTH-SERVICE

Contact Information

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2017 Summary of Advances Discussion

IACC Full Committee Meeting
January 17, 2018

Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination
Executive Secretary, IACC
National Institute of Mental Health

Joshua A. Gordon, M.D., Ph.D.
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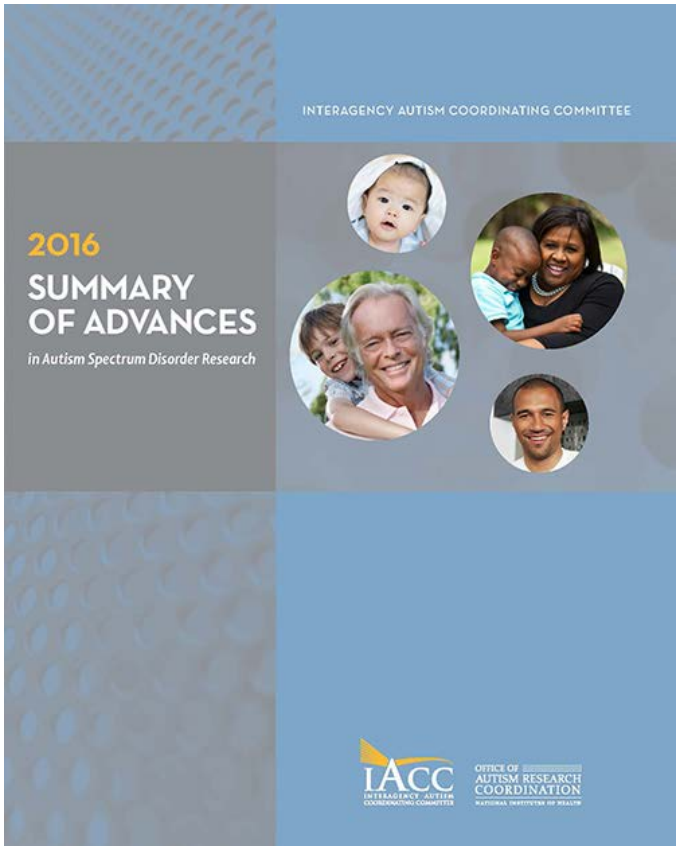
Summary of Advances



- Annual publication required by the Autism CARES Act
- Lay-friendly summaries of the 20 most significant advances in ASD biomedical and services research, as selected by the IACC
- Typically includes articles addressing all 7 topic areas of the IACC Strategic Plan

Summary of Advances Process

- Monthly emails to solicit article nominations from IACC members
- Advances compiled quarterly and discussed at IACC meetings
- **At January IACC meeting, discussion of top articles among those nominated**
- IACC members vote on top 20 articles to be included in 2017 Summary of Advances – **ballots due February 2, 2018**
- Tie-breaker vote (if necessary)

Summary of Advances Process

- Selected articles are summarized
- Nominated articles not selected are listed in the appendix
- Draft publication is prepared and sent out to committee for very brief review
- Final publication is prepared for release
- Target for release – April 2018 IACC meeting

2017 IACC Summary of Advances Nominations Statistics

- 11 IACC members submitted a total of 81 nominations:

  - Question 1 (Diagnosis & Screening): 13
  - Question 2 (Biology): 12
  - Question 3 (Risk Factors): 19
  - Question 4 (Treatments & Interventions): 14
  - Question 5 (Services): 10
  - Question 6 (Lifespan Issues): 9
  - Question 7 (Infrastructure & Surveillance): 4

2017 Summary of Advances Nominations
October – December 2017

Joshua A. Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC

Question 1: Screening and Diagnosis

AUTISM RESEARCH January, 2017 | Volume 10 | Number 1

Sep 2017

Adaptive behavior in autism: minimal clinically important differences on the Vineland-II.
Chatham CH, Taylor KI, Charman T, Liogier D'ardhuy X, Eule E, Fedele A, Hardan AY, Loth E, Murtagh L, Del Valle Rubido M, San Jose Caceres A, Sevigny J, Sikich L, Snyder L, Tillmann JE, Ventola PE, Walton-Bowen KL, Wang PP, Willgoss T, Bolognani F.

The International Journal of Research and Practice Volume 21 Number 5 July 2017
autism

Nov 2017

Race influences parent report of concerns about symptoms of autism spectrum disorder.
Donohue MR, Childs AW, Richards M, Robins DL.

Question 1: Screening and Diagnosis

Journal of Autism and Developmental Disorders

Sep 2017

A prospective study of the concordance of DSM-IV and DSM-5 diagnostic criteria for autism spectrum disorder.
Mazurek MO, Lu F, Symecko H, Butter E, Bing NM, Hundley RJ, Poulsen M, Kanne SM, Macklin EA, Handen BL.

Journal of Autism and Developmental Disorders

Apr 2017

A comprehensive examination of reading heterogeneity in students with high functioning autism: distinct reading profiles and their relation to autism symptom severity.
McIntyre NS, Solari EJ, Grimm RP, E Lerro L, E Gonzales J, Mundy PC.

Question 1: Screening and Diagnosis

Journal of Autism and Developmental Disorders

Nov 2017

Screening for autism with the SRS and SCQ: variations across demographic, developmental and behavioral factors in preschool children.
Moody EJ, Reyes N, Ledbetter C, Wiggins L, DiGuiseppi C, Alexander A, Jackson S, Lee LC, Levy SE, Rosenberg SA.

Journal of Developmental & Behavioral Pediatrics

Apr 2017

Parent-reported strengths in children with autism spectrum disorders at the time of an interdisciplinary diagnostic evaluation.
Sabapathy T, Madduri N, Deavenport-Saman A, Zamora I, Schrager SM, Vanderbilt DL.

Question 1: Screening and Diagnosis

Official Journal of the Society of Biological Psychiatry
Biological Psychiatry

Aug 2017

Increased Extra-axial Cerebrospinal Fluid in High-Risk Infants Who Later Develop Autism.

Shen MD, Kim SH, McKinstry RC, Gu H, Hazlett HC, Nordahl CW, Emerson RW, Shaw D, Elison JT, Swanson MR, Fonov VS, Gerig G, Dager SR, Botteron KN, Paterson S, Schultz RT, Evans AC, Estes AM, Zwaigenbaum L, Styner MA, Amaral DG, Piven J; Infant Brain Imaging Study Network; Infant Brain Imaging Study Network, The Infant Brain Imaging Study (IBIS) Network is a National Institutes of Health–funded Autism Center of Excellence project and consists of a consortium of eight universities in the United States and Canada, Piven J, Hazlett HC, Chappell C, Dager S, Estes A, Shaw D, Botteron K, McKinstry R, Constantino J, Pruett J, Schultz R, Zwaigenbaum L, Elison J, Evans AC, Collins DL, Pike GB, Fonov V, Kostopoulos P, Das S, Gerig G, Styner M, Gu H.

Question 2: Underlying Biology

PNAS
Proceedings of the National Academy of Sciences of the United States of America www.pnas.org

Oct 2017

Longitudinal identification of clinically distinct neurophenotypes in young children with fragile X syndrome.
Bruno JL, Romano D, Mazaika P, Lightbody AA, Hazlett HC, Piven J, Reiss AL.

The Journal of Child Psychology and Psychiatry

Oct 2017

Examining bidirectional effects between the autism spectrum disorder (ASD) core symptom domains and anxiety in children with ASD.
Duvekot J, van der Ende J, Verhulst FC, Greaves-Lord K.

Question 2: Underlying Biology

Cerebral CORTEX

Mar 2017

Joint attention and brain functional connectivity in infants and toddlers.
Eggebrecht AT, Elison JT, Feczko E, Todorov A, Wolff JJ, Kandala S, Adams CM, Snyder AZ, Lewis JD, Estes AM, Zwaigenbaum L, Botteron KN, McKinstry RC, Constantino JN, Evans A, Hazlett HC, Dager S, Paterson SJ, Schultz RT, Styner MA, Gerig G, Das S, Kostopoulos P; IBIS Network, Schlaggar BL, Petersen SE, Piven J, Pruett JR Jr.

AUTISM RESEARCH

Aug 2017

I tawt i taw a puddy tat: Gestures in canary row narrations by high-functioning youth with autism spectrum disorder.
Silverman LB, Eigsti IM, Bennetto L.

Question 2: Underlying Biology

AUTISM RESEARCH

Oct 2017

What will my child's future hold? phenotypes of intellectual development in 2-8-year-olds with autism spectrum disorder.
Solomon M, Iosif AM, Reinhardt VP, Libero LE, Nordahl CW, Ozonoff S, Rogers SJ, Amaral DG.

The Journal of Comparative Neurology

Feb 2018

Protracted dendritic growth in the typically developing human amygdala and increased spine density in young ASD brains.
Weir RK, Bauman MD, Jacobs B, Schumann CM.

Question 3: Risk Factors

Oct 2017

Cross-tissue integration of genetic and epigenetic data offers insight into autism spectrum disorder.
Andrews SV, Ellis SE, Bakulski KM, Sheppard B, Croen LA, Hertz-Picciotto I, Newschaffer CJ, Feinberg AP, Arking DE, Ladd-Acosta C, Fallin MD.

Jun 2017

Identification of developmental and behavioral markers associated with genetic abnormalities in autism spectrum disorder.
Bishop SL, Farmer C, Bal V, Robinson EB, Willsey AJ, Werling DM, Havdahl KA, Sanders SJ, Thurm A.

Question 3: Risk Factors

AUTISM RESEARCH

Nov 2017

Prenatal exposure to fever is associated with autism spectrum disorder in the boston birth cohort.
Brucato M, Ladd-Acosta C, Li M, Caruso D, Hong X, Kaczaniuk J, Stuart EA, Fallin MD, Wang X.

Paediatric and Perinatal Epidemiology

Oct 2017

Maternal multivitamin intake, plasma folate and vitamin B12 levels and autism spectrum disorder risk in offspring.
Raghavan R, Riley AW, Volk H, Caruso D, Hironaka L, Sices L, Hong X, Wang G, Ji Y, Brucato M, Wahl A, Stivers T, Pearson C, Zuckerman B, Stuart EA, Landa R, Fallin MD, Wang X.

Question 3: Risk Factors

npj | Genomic Medicine

Oct 2017

A framework to identify contributing genes in patients with Phelan-McDermid syndrome.

Tabet A, Rolland T, Ducloy M, Lévy J, Buratti J, Mathier A, Haye D, Perrin L, Dupont C, Passemard S, Capri Y, Verloes A, Drunat, S, Keren B, Mignot C, Marey I, Jacquette A, Whalen S, Pipras E, Benzacken B, Chantot-Bastaraud S, Afenjar A, Héron D, Le Caignec C, Beneteau C, Pichon O, Isidor B, David A, El Khattabi L, Kemeny S, Gouas L, Vago P, Mosca-Boidron A, Faivre L, Missirian C, Philip N, Sanlaville D, Edery P, Satre V, Coutton C, Devillard F, Dieterich K, Vuillaume M, Rooryck C, Lacombe D, Pinson L, Gatinois V, Puechberty J, Chiesa J, Lespinasse J, Dubourg C, Quelin C, Fradin M, Journel H, Toutain A, Martin D, Benmansour A, Leblond CS, Toro R, Amsellem F, Delome R, Bourgeron T.

Question 3: Risk Factors

Molecular Autism

Oct 2017

The association between maternal use of folic acid supplements during pregnancy and risk of autism spectrum disorders in children: a meta-analysis.
Wang M, Li K, Zhao D, Li L.

AUTISM RESEARCH

Mar 2017

Severity of ASD symptoms and their correlation with the presence of copy number variations and exposure to first trimester ultrasound.
Webb SJ, Garrison MM, Bernier R, McClintic AM, King BH, Mourad PD.

Question 4: Treatments and Interventions

Journal of Autism and Developmental Disorders

Dec 2017

Feasibility, acceptability and preliminary treatment outcomes in a school-based CBT intervention program for adolescents with ASD and anxiety in Singapore.
Drmic IE, Aljunied M, Reaven J.

Journal of the American Academy of Child & Adolescent Psychiatry

Oct 2017

A randomized, placebo-controlled trial of metformin for the treatment of overweight induced by antipsychotic medication in young people with autism spectrum disorder: open-label extension.
Handen BL, Anagnostou E, Aman MG, Sanders KB, Chan J, Hollway JA, Brian J, Arnold LE, Capano L, Williams C, Hellings JA, Butter E, Mankad D, Tumuluru R, Kettel J, Newsom CR, Peleg N, Odrobina D, McAuliffe-Bellin S, Marler S, Wong T, Wagner A, Hadjiyannakis S, Macklin EA, Veenstra-VanderWeele J.

Question 4: Treatments and Interventions

Journal of Autism and Developmental Disorders

Dec 2017

Intolerance of uncertainty predicts anxiety outcomes following CBT in youth with ASD.
Keefer A, Kreiser NL, Singh V, Blakeley-Smith A, Duncan A, Johnson C, Klinger L, Meyer A, Reaven J, Vasa RA.

The International Journal of Research and Practice Volume 21 Number 5 July 2017
autism

Dec 2017

A pilot investigation of an iOS-based app for toilet training children with autism spectrum disorder.
Mruzek DW, McAleavey S, Loring WA, Butter E, Smith T, McDonnell E, Levato L, Aponte C, Travis RP, Aiello RE, Taylor CM, Wilkins JW, Corbett-Dick P, Finkelstein DM, York AM, Zanibbi K.

Question 4: Treatments and Interventions

PNAS
Proceedings of the National Academy of Sciences of the United States of America www.pnas.org

Jul 2017

Intranasal oxytocin treatment for social deficits and biomarkers of response in children with autism.
Parker KJ, Oztan O, Libove RA, Sumiyoshi RD, Jackson LP, Karhson DS, Summers JE, Hinman KE, Motonaga KS, Phillips JM, Carson DS, Garner JP, Hardan AY.

AHRQ Comparative Effectiveness Reviews

May 2017

Interventions targeting sensory challenges in children with autism spectrum disorder – an update [internet].
Weitlauf AS, Sathe N, McPheeters ML, Warren ZE.

Question 5: Services

International Review of Research in Developmental Disabilities

2017

Strengthening informal supports to promote behavioral health of youth with intellectual and/or developmental disabilities in rural communities.
Hepburn SL.

The International Journal of Research and Practice Volume 21 Number 5 July 2017
autism

Jul 2017

Associations of quality of life with health-related characteristics among children with autism.
Kuhlthau KA, McDonnell E, Coury DL, Payakachat N, Macklin E.

Question 5: Services

Journal of Autism and Developmental Disorders

Nov 2017

Assessing quality of program environments for children and youth with autism: Autism Program Environment Rating Scale (APERS).
Odom SL, Cox A, Sideris J, Hume KA, Hedges S, Kucharczyk S, Shaw E, Boyd BA, Reszka S, Neitzel J.

Question 6: Lifespan Issues

The International Journal of Research and Practice
autism
Volume 21 Number 5 July 2017

Jul 2017

Factors associated with sustained community employment among adults with autism and co-occurring intellectual disability.
Chan W, Smith LE, Hong J, Greenberg JS, Lounds Taylor J, Mailick MR.

AUTISM RESEARCH
January, 2017 | Volume 10 | Number 1

Dec 2017

Cognitive enhancement therapy for adult autism spectrum disorder: Results of an 18-month randomized clinical trial.
Eack SM, Hogarty SS, Greenwald DP, Litschge MY, Porton SA, Mazefsky CA, Minshew NJ.

Question 6: Lifespan Issues

Journal of Autism and Developmental Disorders

Jul 2017

Assessing autism in adults: an evaluation of the Developmental, Dimensional and Diagnostic Interview-Adult Version (3Di-Adult).
Mandy W, Clarke K, McKenner M, Strydom A, Crabtree J, Lai MC, Allison C, Baron-Cohen S, Skuse D.

The International Journal of Research and Practice Volume 21 Number 5 July 2017
autism

Oct 2017

First impressions of adults with autism improve with diagnostic disclosure and increased autism knowledge of peers.
Sasson NJ, Morrison KE.

Morning Break

Meeting of the IACC

Morning Agenda - continued

11:15 **Committee Business**

Susan Daniels, Ph.D.
Director, OARC, NIMH and Executive Secretary, IACC

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

12:00 PM **Lunch**

IACC Committee Business

IACC Full Committee Meeting
January 17, 2018

Susan A. Daniels, Ph.D.
Director, Office of Autism Research Coordination
Executive Secretary, IACC
National Institute of Mental Health

Thanks to OARC Staff

Susan Daniels, Ph.D.
Director

Oni Celestin, Ph.D.
Science Policy Analyst

Julianna Rava, M.P.H.
Science Policy Analyst

Rebecca Martin, M.P.H
Public Health Analyst

Matthew Vilnit, B.S.
Operations Coordinator

Angelice Mitrakas, **B.A.**
Management Analyst

Jeff Wiegand, **B.S.**
Web Development Manager

Karen Mowrer, Ph.D.
Science Policy Analyst

2016 ASD Research Portfolio Analysis

- OARC is currently collecting data for the 2016 *IACC ASD Research Portfolio Analysis Report*
- Using 2016 data, OARC/NIMH/NIH, Autistica (UK), and the Canadian government are planning to collaborate to produce the first International Autism Research Portfolio Analysis
  - Preliminary results of this analysis will be presented at the INSAR annual meeting, May 2018
  - Hope to stimulate broader international participation in future years



Autism CARES Act Report to Congress

- OARC is coordinating the preparation of a report detailing progress on activities related to ASD and other developmental disorders across the federal government – required in the Autism CARES Act

- Requests for data have gone out to relevant federal agencies

- Report expected in Fall 2018

Social Security Administration Request for Information (RFI)

- SSA is soliciting input on strategies to improve adult outcomes for youth receiving Supplemental Security Income (SSI)

- Comments must be received by **February 2, 2018**

- For more information, visit this site: https://www.federalregister.gov/documents/2018/01/03/2017-28397/request-for-information-on-strategies-to-improve-adult-outcomes-for-youth-receiving-supplemental

New IACC Working Groups

- IACC has voted to convene 3 working groups on issues of critical importance to the autism community between January 2018 and September 2019:
  - **Improving Health Outcomes for Individuals on the Autism Spectrum (to start in 2018 Q1)**
  - Housing
  - Safety
- Timing will be staggered to allow timely completion of projects

Improving Health Outcomes for Individuals on the Autism Spectrum WG

- Co-chairs: Dr. David Amaral and Dr. Julie Taylor

- Scope
  - Health and general wellness for individuals with ASD
  - Co-occurring conditions and preventative approaches to address them, e.g. obesity
  - Co-occurring mental health conditions
  - Premature mortality (epilepsy, suicide, chronic health conditions, etc.)
  - Patient-provider interactions
  - Medical practitioner training (i.e. increasing understanding of autism among physicians, supporting community doctors who provide medical care for adults with autism)
  - Parental/family mental health

Improving Health Outcomes for Individuals on the Autism Spectrum WG

Activities:

- Phone meetings to discuss issues
- A written document (i.e., a white paper, report, or published article) outlining challenges and recommendations for health and wellness issues and/or recommendations for the provider community
  - This document can be used toward preparation of the 2018 IACC Strategic Plan update
- Opportunity for a panel discussion on health and wellness issues at the April 2018 IACC meeting:
  - IACC and WG members will submit suggestions for topics and speakers
  - Discussion can contribute to information gathered for preparation of the written document

Health and Wellness WG: Next Steps

- Topic suggestions from the committee?
- Send additional nominations for WG members to OARC by **Wednesday, January 24, 2018**
- First WG conference call planned for February 2018
- Panel discussion at April 2018 IACC meeting

Suggestions for Topics for Future IACC Meetings

- IACC Members – Please suggest topics and speakers for future IACC meeting presentations and panel discussions

Upcoming IACC Meeting

Next IACC Meeting:

Thursday, April 19, 2018

Lunch

Meeting of the IACC

Afternoon Agenda

1:00 **Public Comment Session**

Joshua Gordon, M.D., Ph.D.
Director, NIMH and Chair, IACC

Julianna Rava, M.P.H.
Science Policy Analyst, Office of Autism Research Coordination, NIMH

Meeting of the IACC

Afternoon Agenda - continued

2:00 **Autism Screening**

Introduction to the ASD PEDS Network
Denise Pintello, Ph.D., M.S.W.
Chief, Child and Adolescent Research Program, NIMH
Acting Chief, Dissemination and Implementation Research Program, NIMH

Mobilizing Community Systems to Engage Families in Early Autism Detection & Services
Amy Wetherby, Ph.D., C.C.C.-S.L.P.
Distinguished Research Professor, Department of Clinical Sciences, Florida State University
Director, Autism Institute, Florida State University

Meeting of the IACC

Afternoon Agenda - continued

Multi-Stage Screening in Part C Early Intervention Address Health Disparities in Age of ASD Diagnosis and Service Receipt

Alice Carter, Ph.D.

Professor, College of Liberal Arts, University of Massachusetts, Boston

Leveraging Urban Primary Care Systems to Improve Early Identification of Low-Income Children with Autism Spectrum Disorder

Emily Feinberg, Sc.D. C.P.N.P.

Associate Professor, Department of Community Health Sciences, Boston University School of Public Health

Associate Professor of Pediatrics, Division of General Pediatrics, Boston University School of Medicine

Meeting of the IACC

Afternoon Agenda - continued

3:30	**Committee Discussion**
4:00	**Afternoon Break**
4:15	**Round Robin**
5:00	**Closing Remarks and Adjournment**

Oral Public Comment Session

Joshua Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC

Julianna Rava, M.P.H.
Science Policy Analyst, Office of Autism Research Coordination
National Institute of Mental Health

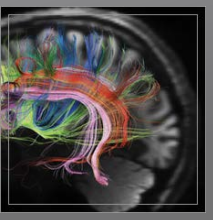
Written Public Comment Session

Joshua Gordon, M.D., Ph.D.
Director, National Institute of Mental Health
Chair, IACC

Julianna Rava, M.P.H.
Science Policy Analyst, Office of Autism Research Coordination
National Institute of Mental Health

Autism Screening Panel Presentation

Denise Pintello, Ph.D., M.S.W.
Amy Wetherby, Ph.D., C.C.C.-S.L.P.
Emily Feinberg, Sc.D. C.P.N.P.
Alice Carter, Ph.D.



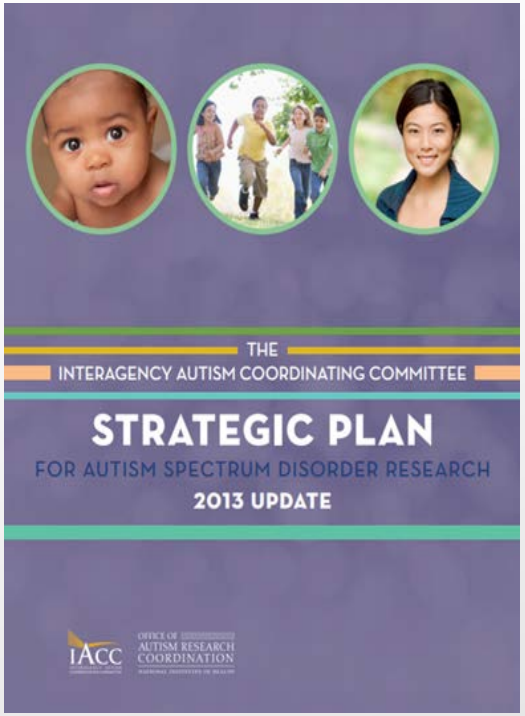

Introduction to the ASD PEDS Network

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

January 17, 2018

National Institute of Mental Health

Origin of ASD PEDS Network Research Studies



2013 STRATEGIC PLAN for Autism Spectrum Disorder Research

IACC INTERAGENCY AUTISM COORDINATING COMMITTEE

NIH National Institute of Mental Health

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

NIH National Institute of Mental Health

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

National Institute of Mental Health

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

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
Related Notices	• October 18, 2013 - See Notice NOT-OD-14-003. Guidance on Resumption of NIH Extramural Activities Following the Recent Lapse in Appropriations. • August 21, 2013. Removed reference to ASSIST in section IV.3, since ASSIST is currently only available for multi-project applications. • May 30, 2013 (NOT-OD-13-074) - NIH to Require Use of Updated Electronic Application Forms for Due Dates on or after September 25, 2013. Forms-C applications are required for due dates on or after September 25, 2013.
Funding Opportunity Announcement (FOA) Number	RFA-MH-14-100

National Institute of Mental Health

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

National Institute of Mental Health

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

FIVE FUNDED RESEARCH STUDIES

	Karen Pierce	University of California San Diego	Detection of ASD at the 1st birthday as standard of care: The Get SET Early Model

This study is testing a three-stage early intervention model system known as Get S.E.T. Early (S=Screen, E=Evaluate, T=Treat) in San Diego and Phoenix, and is designed to detect, evaluate, and treat ASD within the first 2 years

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

	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

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
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); Phoenix: 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	16-27 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	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; SCRF; 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

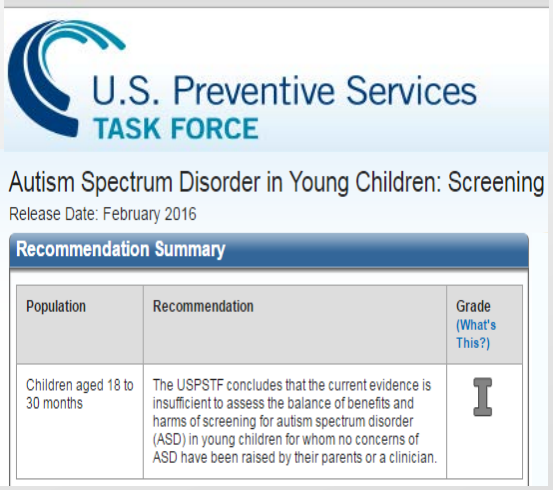
Four Common Measures are Being Utilized

- 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


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."

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
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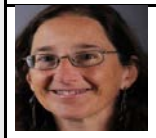
	Alice Carter, Radley Sheldrick	University of Massachusetts Boston	Addressing Systemic Health Disparities in Early ASD Identification and Treatment
	Amy Wetherby, Catherine Lord, Ami Klin, Craig Newschaffer	Florida State University; Emory University; Drexel University; Weill Cornell Medical College	Mobilizing Community Systems to Engage Families in Early ASD Detection and Services

Mobilizing Community Systems to Engage Families in Early Autism Detection and Services

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

Autism Screening: Panel Presentation by the ASD PEDS Network

Meeting of the Interagency Autism Coordinating Committee

January 17, 2018

Bethesda, Maryland

The Problem: The lifetime societal cost for one child with autism is $1.4 to $2.4 million

Buescher, Cidav, Knapp, & Mandell (2014) *JAMA Pediatrics, 168(8):721-728*

Recommendations of the American Academy of Pediatrics (2007)

- Developmental surveillance at every well-child visit from 9 to 30 months
- Screen all children for ASD at 18 and 24 months

✔ Autism can be diagnosed by 18-24 months, yet the median age of diagnosis of ASD is 4-5 years in the US

✔ Children of minority, low income, and rural families are diagnosed a year and a half later.

US Preventive Services Task Force Recommendation Statement

Screening for Autism Spectrum Disorder in Young Children (18 to 30 months)

JAMA, 2016;315(7):691-696

Recommendation: The USPSTF concludes that the current evidence is insufficient to assess the balance of benefits and harms of screening for ASD in young children for whom no concerns of ASD have been raised by their parents or a clinician.

Selection Bias that Inflates Sensitivity/Specificity…

if the average developmental level is far below 75

Screener	*Mullen Scales of Early Learning* Standard Scores (*M*=100; *SD*=15)			
	Visual Rec	Fine Motor	Rec Lang	Exp Lang
Younger Sibs (n = 38) Ozonoff et al. (2015)	89	91	75	75
M-CHAT (n = 105) Robins et al. (2014)	70	68	61	63
ESAC (n = 179) Wetherby et al. (2015)	83	78	76	76

Selection Bias that Inflates Sensitivity/Specificity…

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	6,026	m=16.4	90	14.94

Need to Improve Early Identification of Developmental Disabilities

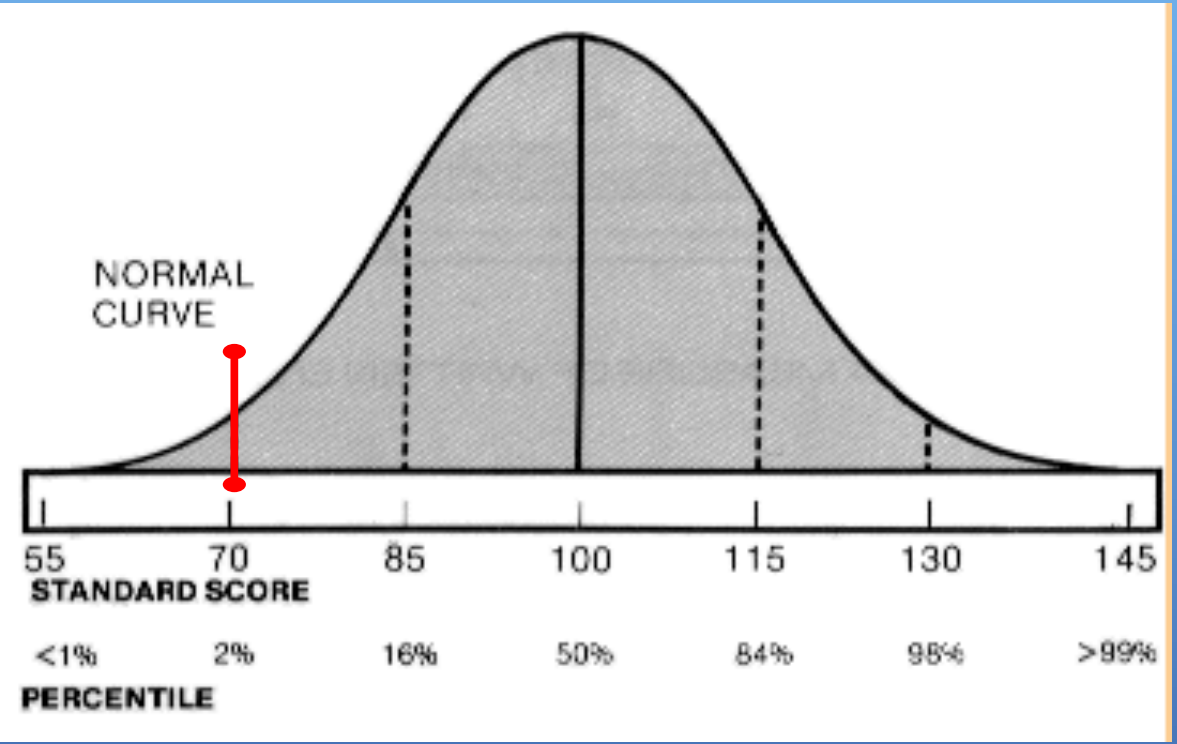
Percentage of Population Receiving Special Education or Early Intervention Services in 2007:

- 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%

✔ This means, 80% of children are missed.

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

Where do we draw the line?



SD	SS	%ile
0.00	100	50th
-1.00	85	16th
-1.25	81	10th
-1.50	77	7th
-2.00	70	2nd

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.

Learn the Signs. Act Early.

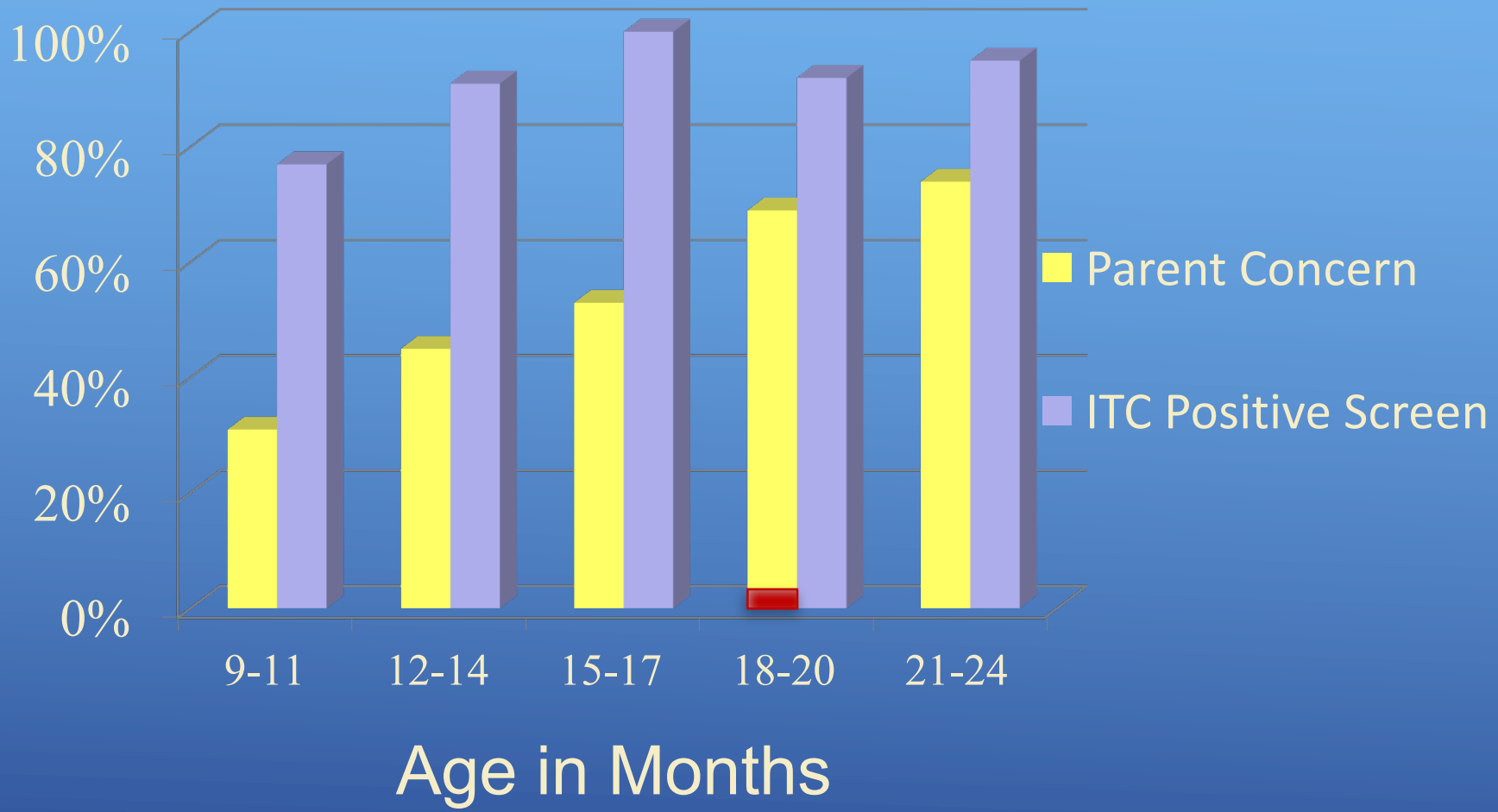
Are these milestones contributing to the solution or the problem?

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

Parent Concern is Less Accurate at Younger Ages…
and this will widen the health disparity

- 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
- Very few reported concerns are 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.

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



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

Funded by NICHD, CDC, NIDCD, & NIMH

www.FirstWordsProject.com

PI: Amy M. Wetherby, Ph.D.
Florida State University

Smart ESAC to streamline screening

Early Screening for Autism & Communication Disorders

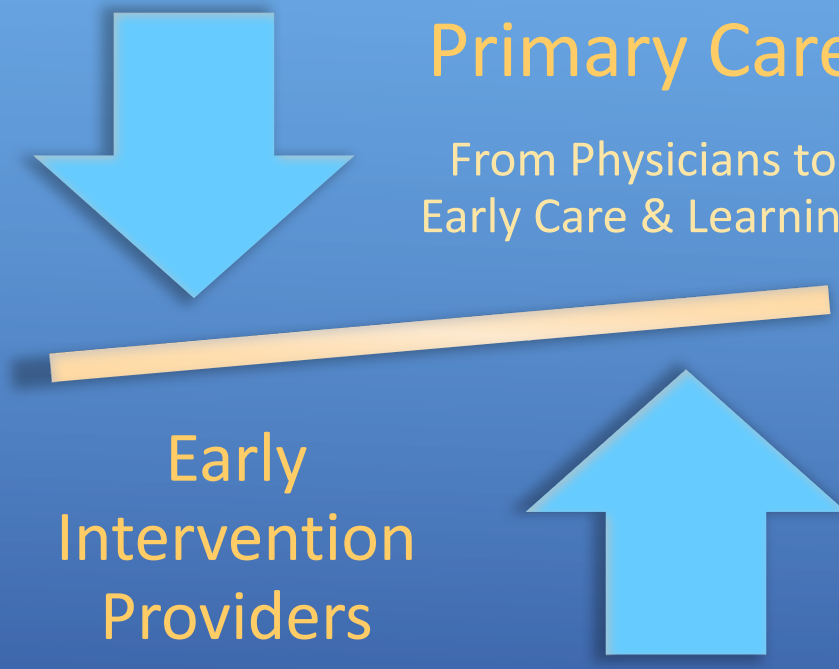
- Online automated system for well-child visits at 9 to 30 months
  - ✓ 10 questions for universal screen for communication delay
  - ✓ Seamlessly followed by 20 questions to screen for autism
  - ✓ Linkages to parent & provider portal, e-monitoring, and online resources and tools for families
- Built by Prometheus Research in collaboration with the FSU Autism Institute

Funded by NIH/NICHD and the State of Florida

So far so good…

- *ESAC* is a promising universal screening tool to distinguish children with ASD from DD and TD between 12-36 months
- ROC curves on our combined samples show very good AUC and good Sensitivity and Specificity at 24-36 months, 18-23 months, and 12-17 months
- Cost-effective screener for ASD that maximizes the role of parents and helps build consensus on red flags in 2 domains

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



Mobilizing Community Systems to Engage Families in Early ASD Detection & Services

Services Research for ASD R01 Grant funded by NIMH

Investigative Team

Amy M. Wetherby, PhD, Florida State University

- Heather Flynn, PhD, Elizabeth Slate, PhD, Jo Brown, MD, Juliann Woods, PhD

Ami Klin, PhD, Emory University

- Jennifer Stapel-Wax, PsyD

Catherine Lord, PhD, Weill Cornell Medical College

Craig Newschaffer, PhD, Drexel University

- Renee Turchi, MD, Paul Shattuck, PhD, Connor Kerns, PhD, Diana Robins, PhD

Reverend Anthony Evans, President of the National Black Church Initiative (NBCI)

David Mandell, ScD, University of Pennsylvania

Roy Richard Grinker, PhD, George Washington University

Debra L. Tsutsui, MPP, Director, Behavioral Health & DD Administration

Alycia Halladay, PhD, Autism Science Foundation

Amy Daniels, PhD, Simons Foundation

Mobilizing Community Systems to Engage Families in Early ASD Detection & Services

Services Research for ASD R01 Grant funded by NIMH

Research Sites and Community Service Systems

Five collaborative research sites:

- Florida State University – FL *(PI: Amy Wetherby)*
- Emory University – GA *(PI: Ami Klin)*
- Drexel University – PA *(PI: Craig Newschaffer)*
- Weill Cornell Medical College– NY *(PI: Cathy Lord)*
- University of Miami – FL (Site-PI: Michael Alessandri)

Three community service systems:

1. Primary care
2. Publicly-funded social service programs
3. National Black Church Initiative (NBCI) and other faith-based organizations

Research Approach: *Planning Phase*

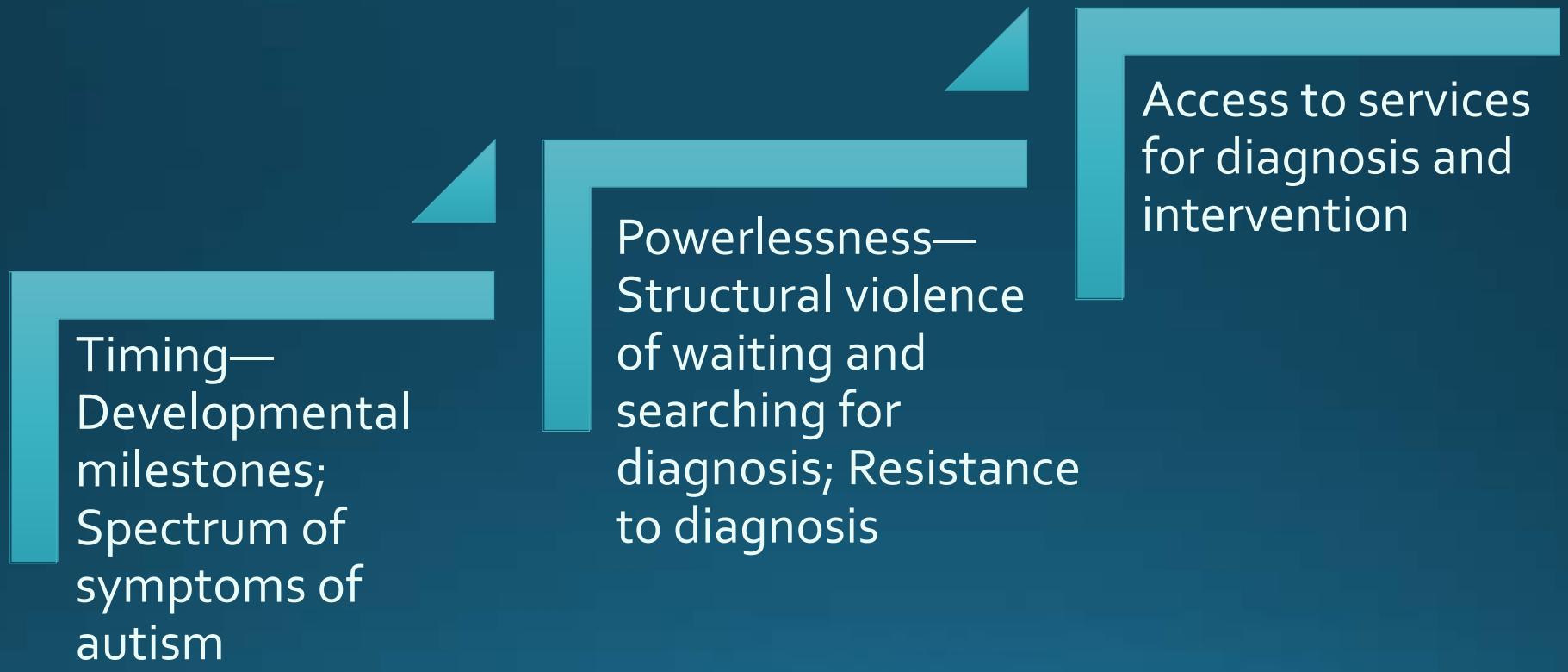
Qualitative research methods using focus groups with families and providers designed …

1) to identify challenges and barriers to early detection and access to early intervention for children under 24 months, and
2) to develop strategies to promote early detection and early intervention in underserved populations.

Focus Groups with Professionals (*n*=50): Overcoming Barriers to Improving Early Detection of ASD in Community Systems

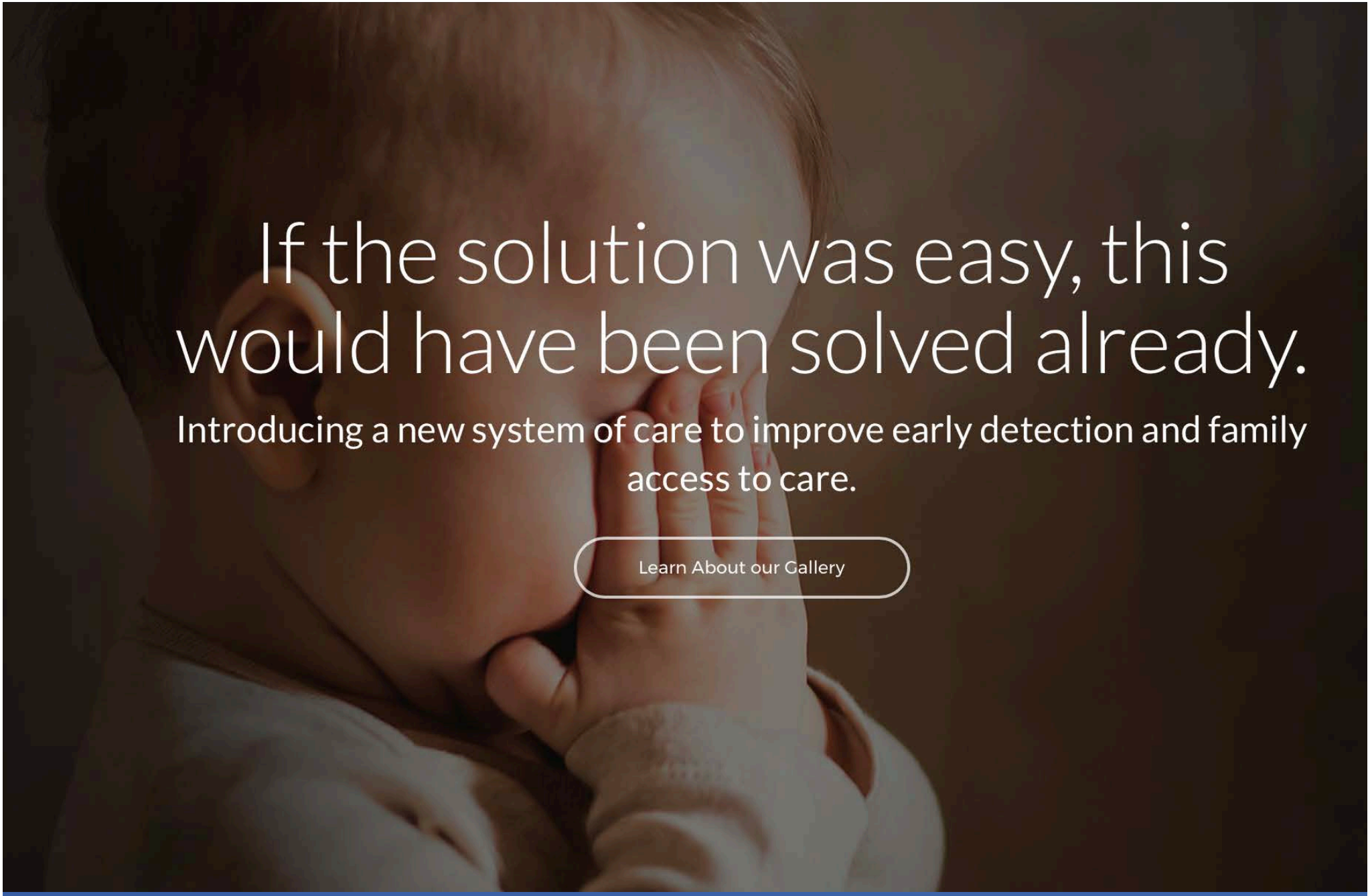
- Training on the early signs of ASD; Wait and see if more comforting
- Available validated screening tools feasible for primary care
- Available intervention services if screening is implemented

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



Research Approach: *Implementation Phase*

- Community Service Providers (CSPs) from the 3 service systems are invited to use the Autism Navigator for Primary Care course, the Smart ESAC, and online portal.
- Using an implementation science framework, initial implementation phase in FL, GA, PA in Year 2. Full implementation was deployed in Year 3 by scaling up in these sites and expanding to NY & Miami.
- We have recruited 396 CSPs in 4 states, 68% from primary care and 32% from other service systems; 166 of the CSPs have completed the coursework and are actively screening.
- CSPs have screened 5,010 toddlers 9-18 months of age with a mean age of 14.25 months. The sample include 51.1%males, 43.7% racial minority, and 36.0% ethnic minority,
- Children with a positive ASD screen are invited for a confirmatory diagnosis at 18, 24, & 36 months to compare short and long-term impact.



www.AutismNavigator.com

Leveraging the Laws of Motion to Generate Forward Movement:

We need all 3 wheels for balance and acceleration.

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

This 30-hour course launched in the 2014.

Autism NAVIGATOR® for Primary Care

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

This 8-hour course launched in the Fall, 2015.

Recognizing Social Communication Features

Typical Development	Early Signs of ASD
	
Charlie at 16 months	Luke at 15 months

1 2 3

Recognizing Social Communication Features

Typical Development	Early Signs of ASD
	
Charlie at 27 months	Luke at 28 months

1 2 3

Provider Materials

Smart ESAC Resources

Research Briefs

Family Materials

English

Spanish

Websites

e-Documents

About Tools

Family Materials (English)
Print materials designed for providers to share with families about specific topics and content covered in each unit and to offer ideas or suggestions on how to monitor and support their child's development. Click on the thumbnail images to open, save, or print a document. Scroll down to view the complete set of documents.

Babies Learn at an Amazing Rate
Milestones of social communication development from 9 to 24 months in English.

16 by 16 Series
The 16 by 16™ series highlights early social communication milestones that children should develop by 16 months of age. It covers 5 developmental domains—16 gestures, 16 actions with objects, 16 ideas to communicate, 16 ways to manage emotions, and 16 messages to understand, from 9 to 16 months to launch language learning and literacy. The series is a companion to the Social Communication Growth Charts and can provide a roadmap to help families and others learn about these important early milestones so they can notice small delays early in order to prevent bigger delays later. **(NOTE: The 16 by 16 series is UNDER DEVELOPMENT. As each new domain is ready it will be added to this PDF.)**

How Parents Can Support Social Communication Development
Description of three layers of supports that all families can use in everyday activities to foster their child's social communication development.

HOW DO WE ENGAGE PROFESSIONALS IN ONLINE COURSES?

Autism NAVIGATOR® for Primary Care

- Course Introduction
- Jump-Start to Primary Care
- 1. Core Diagnostic Features
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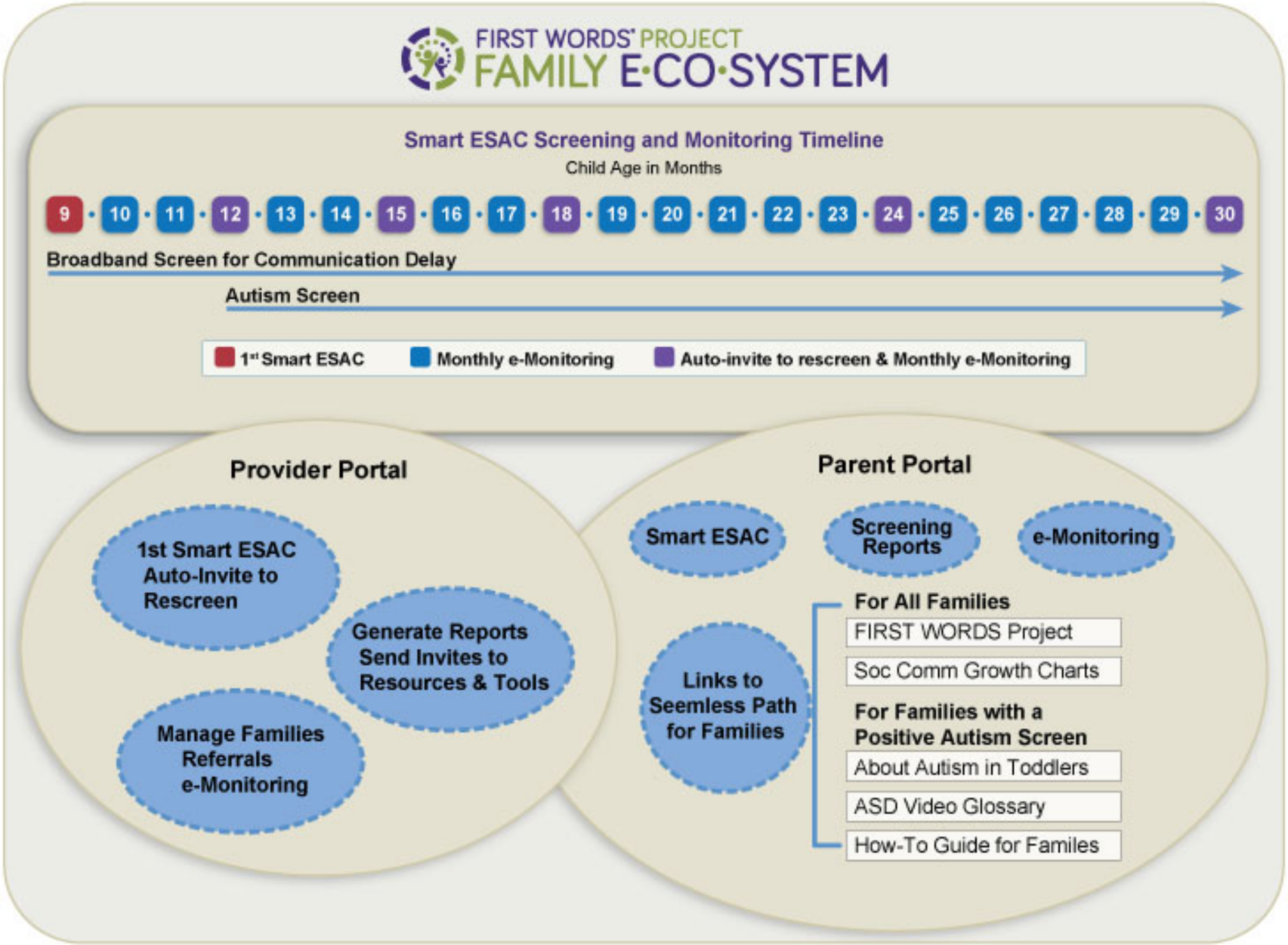
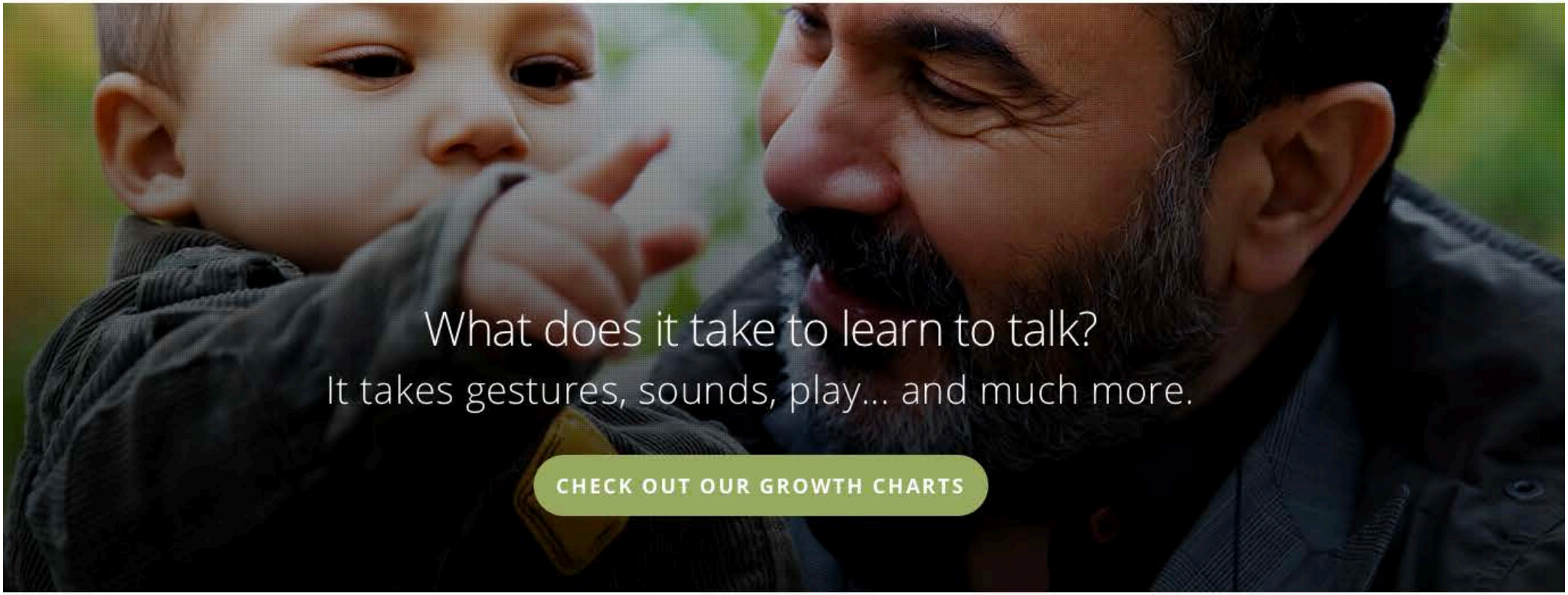


Seamless Path for Families

For all families

FIRST WORDS PROJECT

E•Co•System About 16by16 Growth Charts Resources About Screen My Child



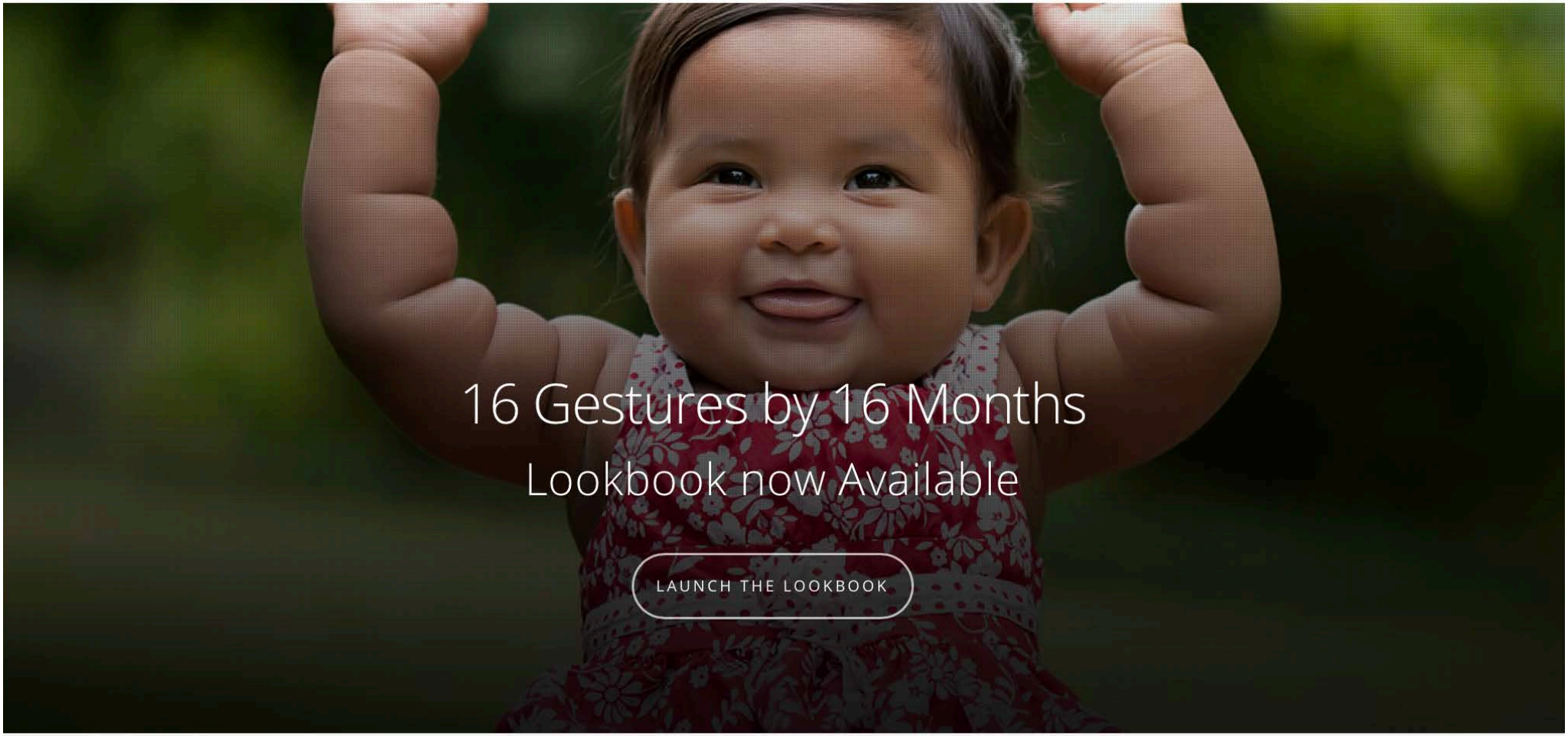
Watch, Learn, and Spread the Word

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

www.FirstWordsProject.com

FIRST WORDS PROJECT

16 by 16 | Growth Charts | Resources | About | Get Involved | Contact



16by16™


16 by 16™
16 GESTURES BY 16 MONTHS
FIRST WORDS PROJECT

16by16

10 MONTHS: REACH, RAISE ARMS

16 GESTURES BY 16 MONTHS

FIRST WORDS PROJECT

16by16

10 MONTHS: REACH, RAISE ARMS

16 GESTURES BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

11 MONTHS: SHOW, WAVE

16 GESTURES BY 16 MONTHS

FIRST WORDS PROJECT

16by16

12 MONTHS: OPEN-HAND POINT, TAP

16 GESTURES BY 16 MONTHS

FIRST WORDS PROJECT

16by16

13 MONTHS: CLAP, BLOW A KISS

At 13 months, children begin to learn by observing others and copying what they do and say. They learn to use gestures, like a clap ...

16 GESTURES BY 16 MONTHS

FIRST WORDS PROJECT

16by16

13 MONTHS: CLAP, BLOW A KISS

... and blow a kiss, just by watching others and imitating them.

16 GESTURES BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

14 MONTHS: INDEX-FINGER POINT, SHHH GESTURE

Children also use the index finger for the "shhh" gesture.

16 GESTURES BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

15 MONTHS: HEAD NOD, THUMBS UP, HAND UP

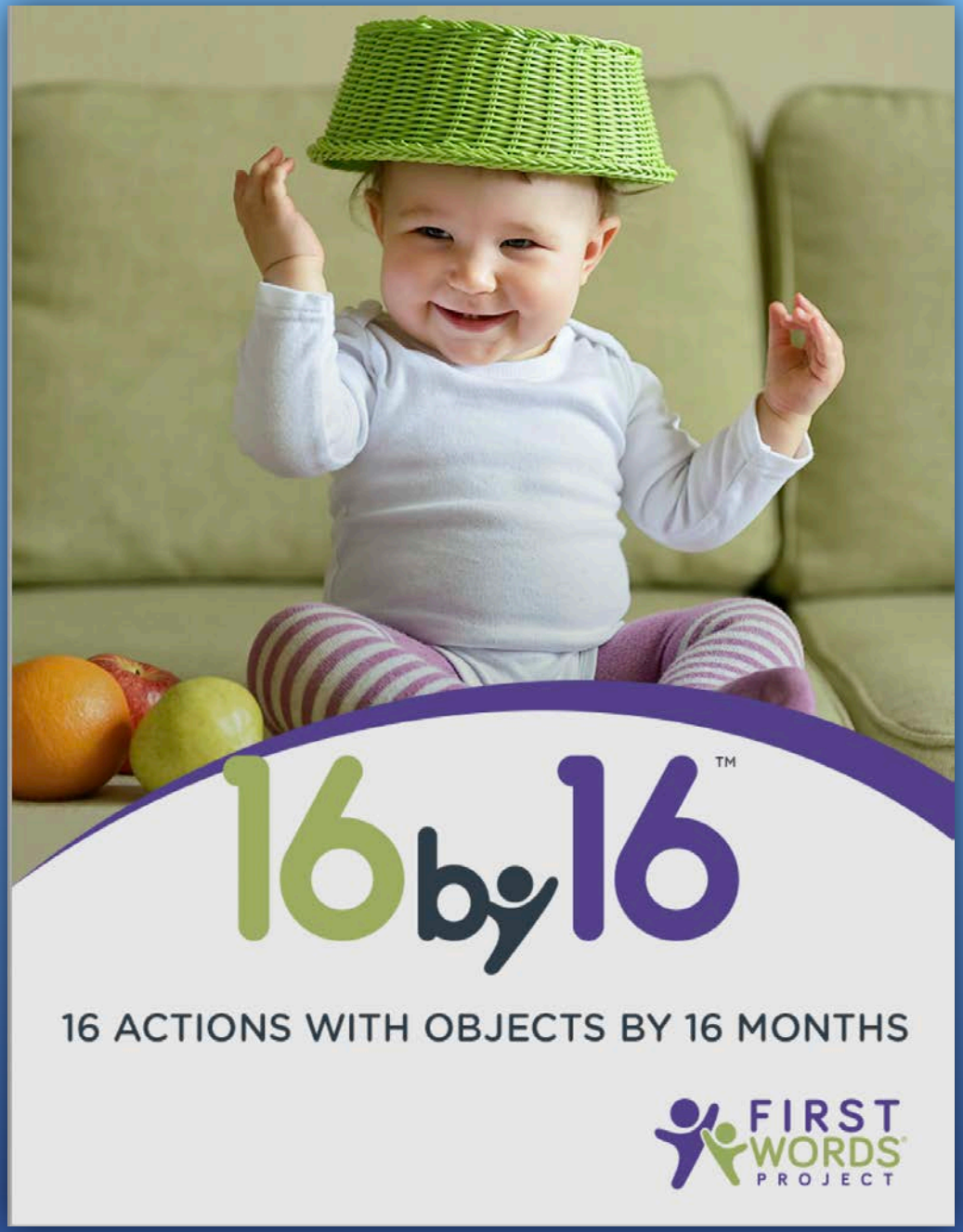
16 GESTURES BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

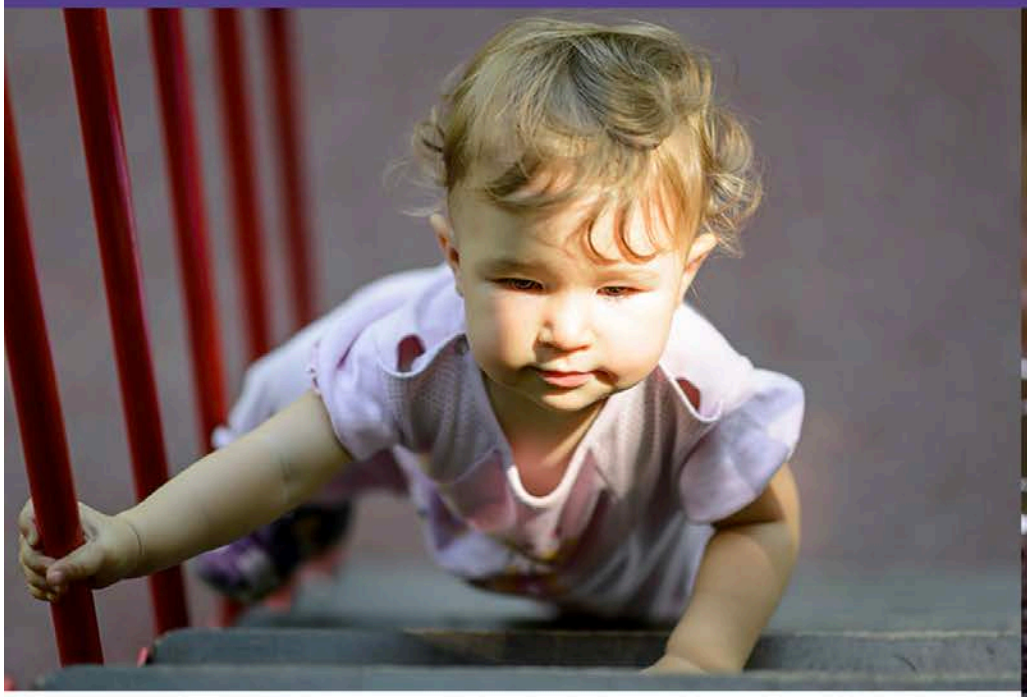
16 MONTHS: OTHER SYMBOLIC GESTURES

Sneak Peek at our New Lookbook being launched this week!



16by16

TODDLERS ARE MOVERS AND SHAKERS



Toddlers are “movers and shakers” — always on the go. They seek information about the world. They experiment to figure out how things work. Their enthusiasm to share their experiences and accomplishments is contagious.

16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

9 MONTHS: MOUTH, BANG, DROP

At 9 months, babies repeat different actions with objects. They mouth objects to explore the features.

FIRST WORDS® PROJECT

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10 MONTHS: TAKE OFF, TAKE OUT

At 10 months, babies learn to grab and pull — and take things off, like a sock, shoe, or hat.

FIRST WORDS® PROJECT

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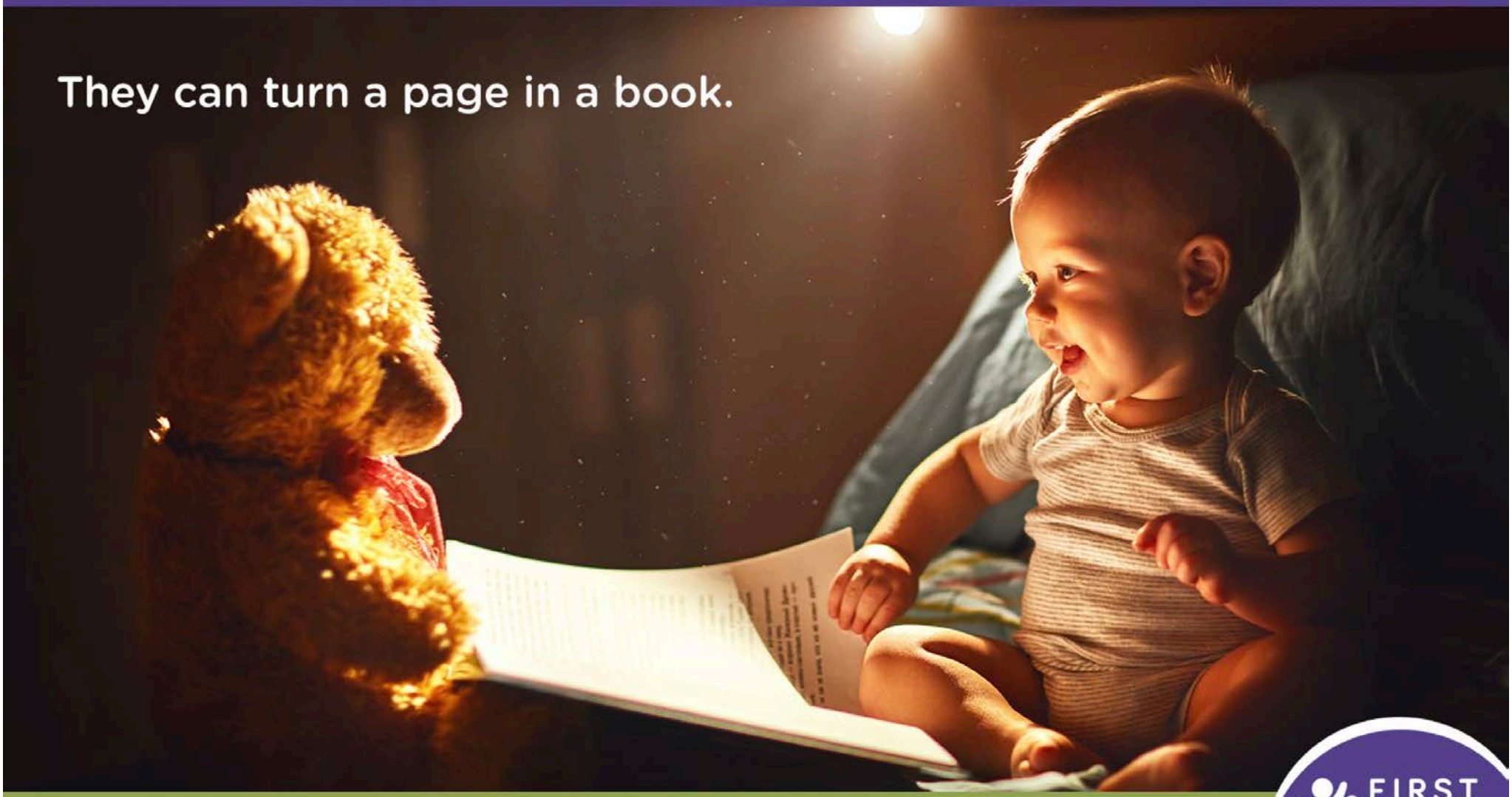
11 MONTHS: MONTHS: PUSH, TURN

They can push a toy train to make it move or a tower of cups to knock it down.

FIRST WORDS® PROJECT

16by16

11 MONTHS: PUSH, TURN



16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS PROJECT

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11 MONTHS: PUSH, TURN

And they can turn a basket upside down, put it on their head, and make you laugh.

FIRST WORDS® PROJECT

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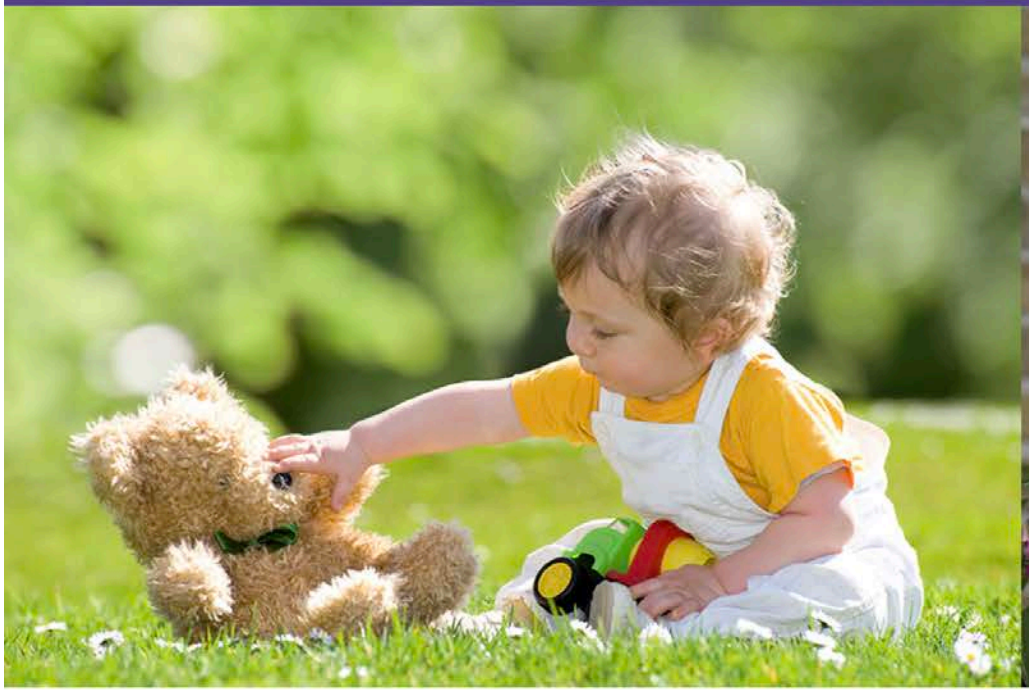
12 MONTHS: PAT, PUT IN



Soon, their pat develops into a hug to share their love.

16by16

12 MONTHS: PAT, PUT IN

At 12 months, babies are learning functional actions with a purpose in mind. They can put things in — put clothes in the dryer or a shape in a puzzle.

FIRST WORDS® PROJECT

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12 MONTHS: PAT, PUT IN

From "put in" they learn a variety of functional actions. They can put a sippy cup in their mouth to drink, ...

FIRST WORDS® PROJECT

16by16

12 MONTHS: PAT, PUT IN

16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS® PROJECT

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13 MONTHS: FEED OTHERS, OPEN & CLOSE

At 13 months, children begin to learn by observing others and copying what they do and say. They can feed Mom with a cup or Teddy bear with a bottle, showing they are on the cusp of pretending.

FIRST WORDS® PROJECT

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14 MONTHS: MOVE OBJECTS BACK & FORTH, UP & DOWN

They jiggle a pan with invisible stuff in it to pretend to cook.

16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS® PROJECT

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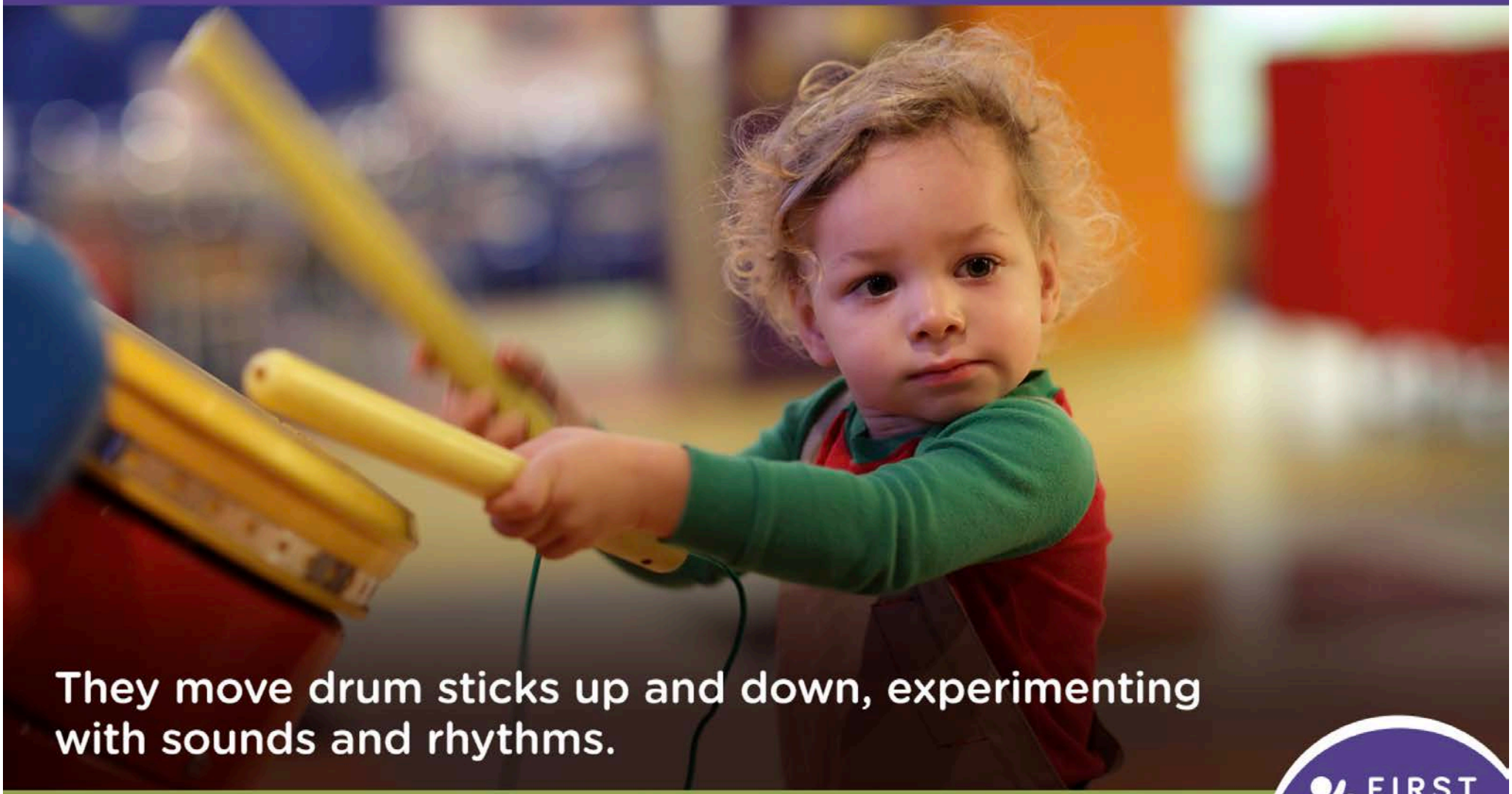
14 MONTHS: MOVE OBJECTS BACK & FORTH, UP & DOWN



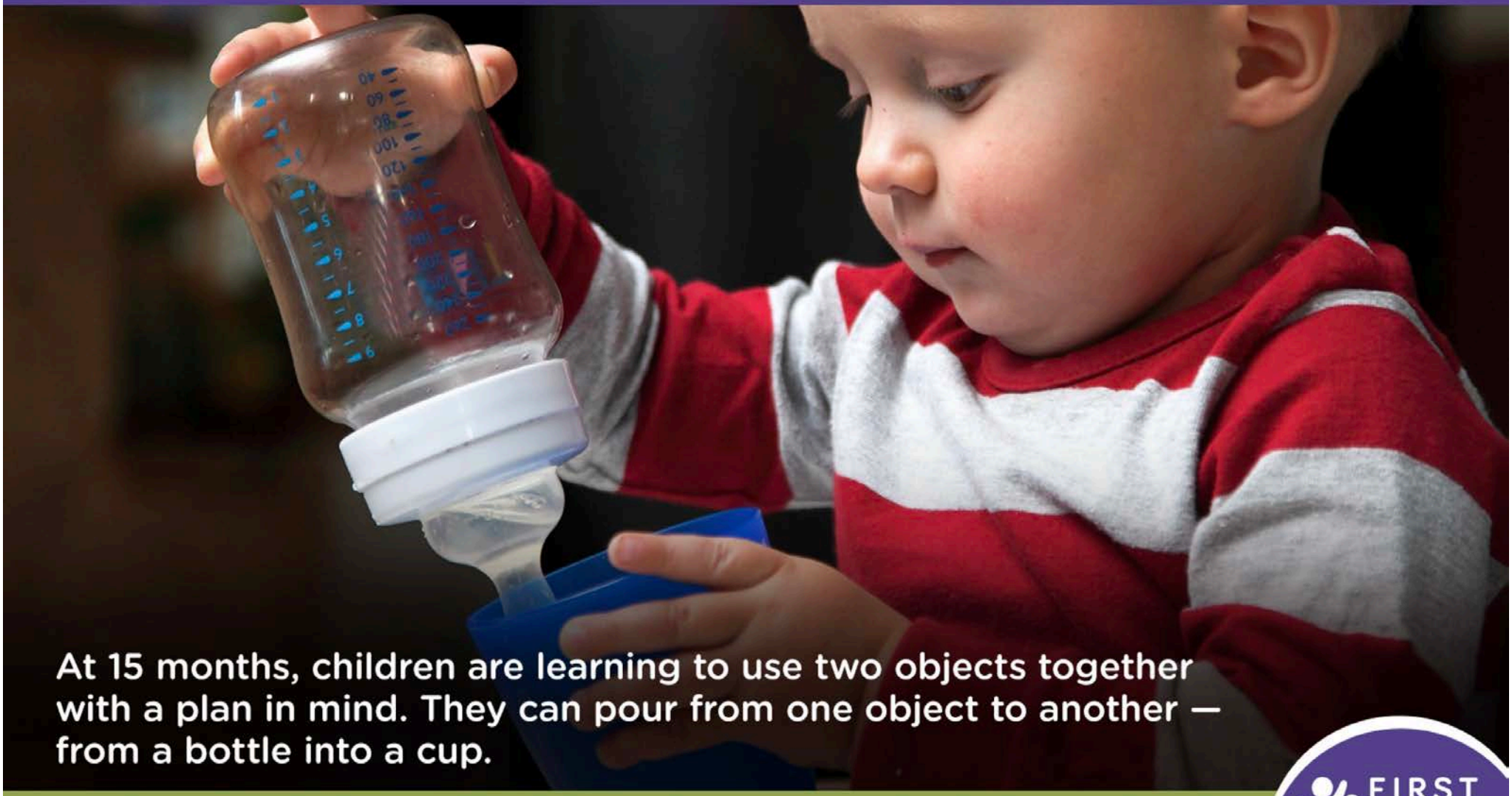
They move drum sticks up and down, experimenting with sounds and rhythms.

16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

15 MONTHS: POUR, WASH & DRY



At 15 months, children are learning to use two objects together with a plan in mind. They can pour from one object to another — from a bottle into a cup.

16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

15 MONTHS: POUR, WASH & DRY

With a plan in mind, they can help wash and dry dishes and even the car. Toddlers are eager for a role in family chores.

FIRST WORDS PROJECT

16by16

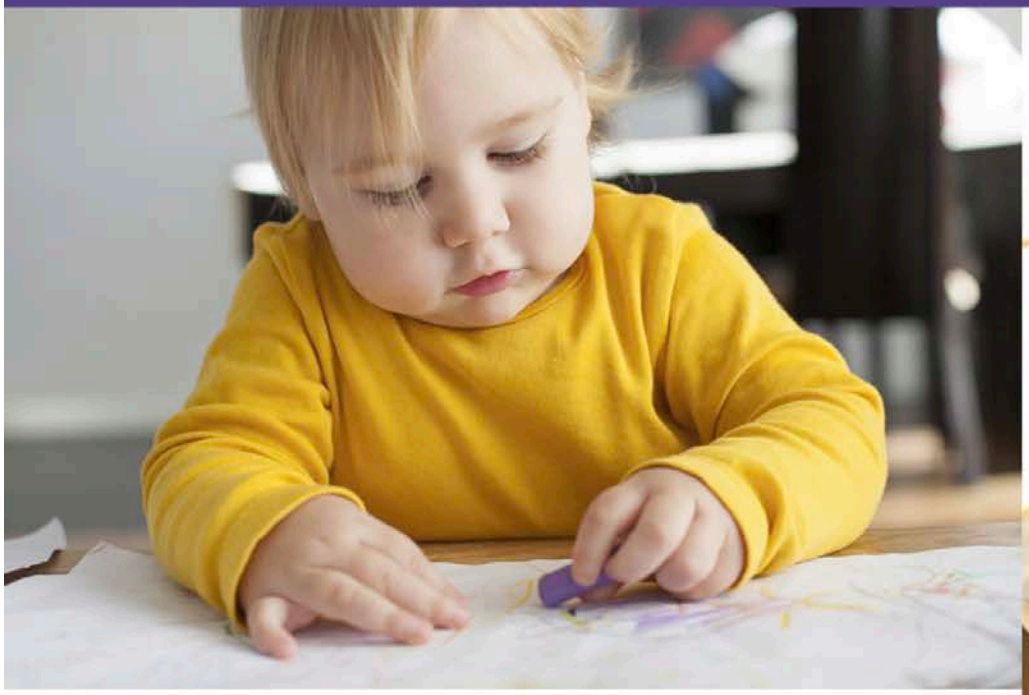
16 MONTHS: STACK, CUT OUT, SCRIBBLE, DRAW

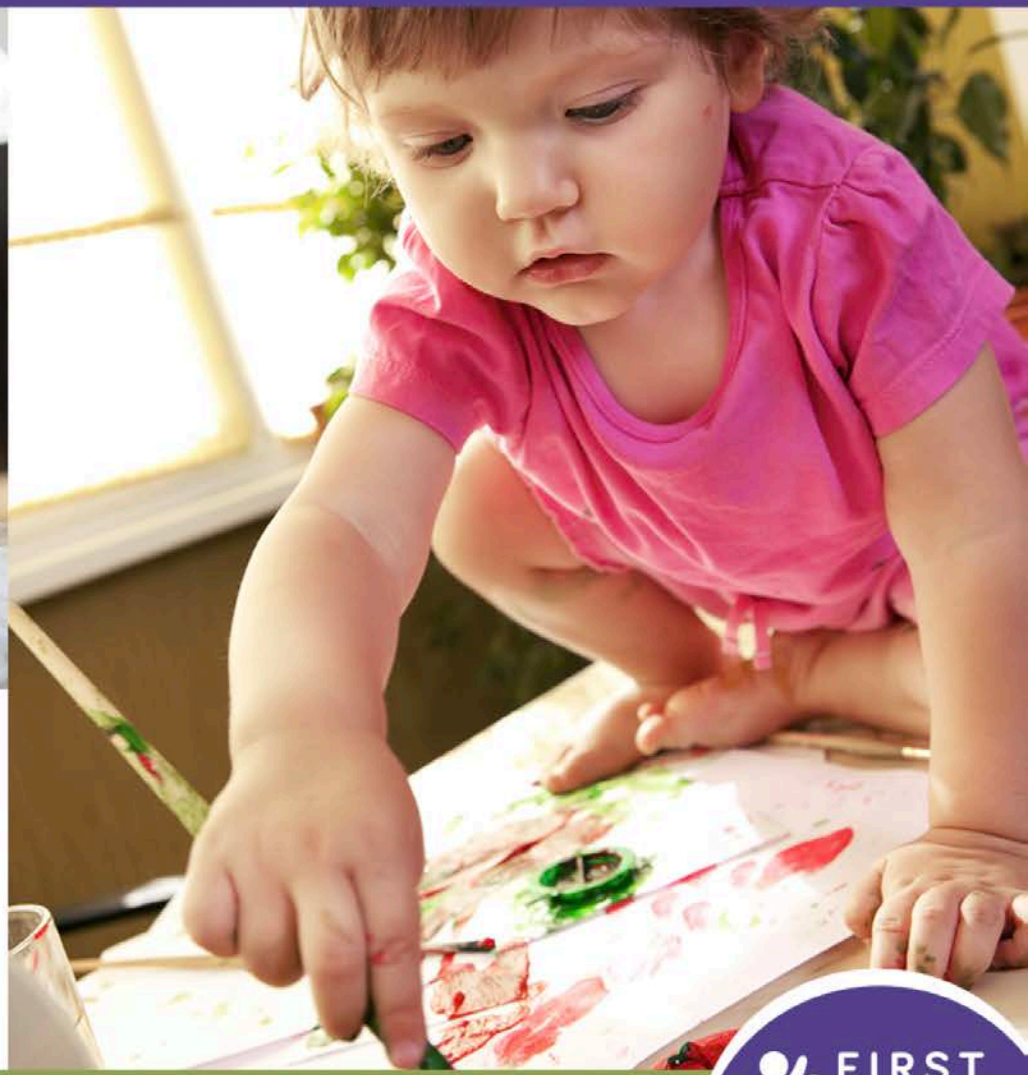
At 16 months, children can make and create things. They can stack 3 or 4 blocks to make a tower.

FIRST WORDS® PROJECT

16by16

16 MONTHS: STACK, CUT OUT, SCRIBBLE, DRAW





Children are learning how to create drawings. They can scribble with a crayon and paint with a paint brush.

16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

16 MONTHS: STACK, CUT OUT, SCRIBBLE, DRAW

With a little help and practice, they try to draw with colored pencils.

16 ACTIONS WITH OBJECTS BY 16 MONTHS

FIRST WORDS® PROJECT

16by16

THE BEST TIME TO GET READY FOR PRESCHOOL IS FROM 9 TO 16 MONTHS

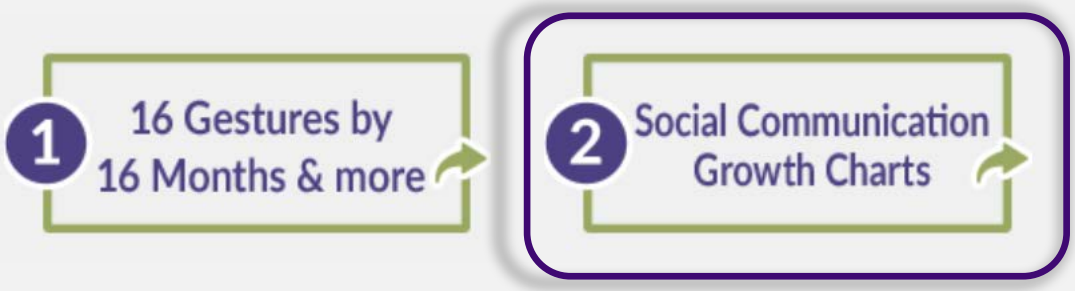
Spotting small gaps in early actions with objects and gestures from 9 to 16 months is the best time to get ready for preschool so children can reach their potential by kindergarten.

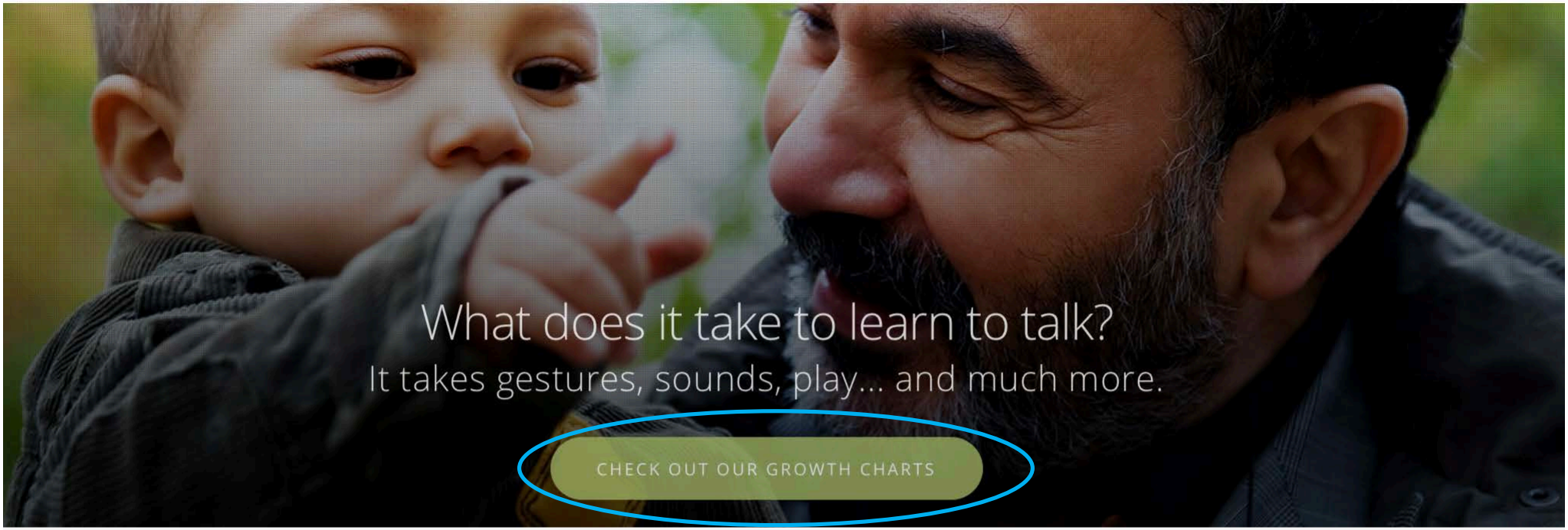
16 ACTIONS WITH OBJECTS BY 16 MONTHS

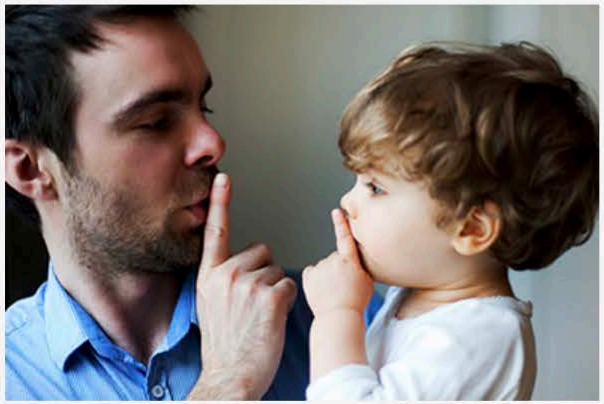
FIRST WORDS® PROJECT

Seamless Path for Families

For all families







16 by 16 Series

Did you know that children should use at least 16 gestures by 16 months?

LEARN MORE

Growth Charts

Learn the Milestones in our Guided Tour for Families of Children 6-24 Months

FIND OUT HOW

Resources

Documents and Websites. Download. Print. Share.

VIEW RESOURCES

SOCIAL COMMUNICATION™ GROWTH CHARTS

Membership | My Charts | FIRST WORDS® Project | About | Sign out

Babies learn at an amazing rate.
Learn the milestones that develop from 7 to 24 months.

Select your child's age.

7-8 | 9-10 | 11-12 | 13-14 | 15-16 | 17-18 | 19-20 | 21-22 | 23-24

Explore Hundreds of Videos. Chart Your Child's Growth.

How Does a Parent Know What to Expect:

Social Communication Developmental Milestones can be a Roadmap

SOCIAL COMMUNICATION™ GROWTH CHARTS

Milestones that Matter Most
7-8 months

Language

Gestures & Meanings

❑ I can use my hands to take things and move my body toward what interests me.

- Reach out to touch your hair or jewelry
- Wiggle and scoot closer to something I'm interested in
- Reach to grab bubbles in the bathtub
- Reach out to pick up a piece of banana from my high chair tray
- Hold a toy in one hand and reach out to pat the dog

Sounds & Words

❑ I can make different noises with my mouth and different sounds.

- Make excited squealing noises as I crawl toward you on the floor
- Whine when I drop my toy out of reach
- Make raspberry noises so you'll laugh again
- Say "ba ba ba" while I'm bouncing in my swing
- Make sounds like "ma ma ma" while waiting for my food to be ready

Play

Using Actions with Objects

❑ I can grasp, hold, bang, mouth, and let go of objects to explore how they work.

- Shake a rattle to make noise
- Bring a toy to my mouth to chew on it
- Hold a toy in each hand and bang them together
- Grab, bang, and drop plastic spoons on the kitchen floor
- Reach out with both hands to touch a stuffed animal

Social Sharing with Objects

❑ I am interested in exploring objects with you and noticing your reactions.

- Reach to take a toy you give me while you're changing my diaper
- Laugh when you hide behind the blanket and then reappear
- Watch to see if you notice when I make a loud noise playing with pots and pans
- Hold my spoon out while I'm eating and notice that you're watching
- Bounce and kick my legs in my car seat and look to see if you're watching me

Social Interaction

Social Attention

❑ I notice you, look at you often, and can easily shift my attention to you when you talk or gesture.

- Watch you wash the dishes while I eat my snack
- Giggle and look at you when you are about to tickle my toes
- Look up at you when you walk in the room, even if I'm playing with toys
- Watch as you sing and clap your hands and reach out to touch them
- Crawl to you as you call my name and hold out your arms

Intentional Communication

❑ I am learning you are the agent of change.

- Reach and look at you when you're holding something I want
- Use a loud voice and then notice that I got your attention
- Turn away from you when I'm finished eating
- Cry and look to you for help when I've dropped something
- Kick my feet excitedly and look at you when I see you coming to pick me up

Emotional Regulation

Sharing & Managing Emotions

❑ I can smile, laugh, and use my voice when I'm happy.

- Laugh and look at you when you make a silly noise
- Squeal with excitement when Grandma is about to pick me up
- Make happy sounds when I see you coming with my cup
- Giggle and look at you when the dog licks my arm
- Bounce up and down and use my excited voice when big brother comes in the room

Regulating Challenging Moments

❑ I can use different actions and sounds, in addition to crying, when I'm upset.

- Cry and lay my head on my tray when my spoon falls down
- Whine and kick away my diaper while you're trying to change me
- Grab your arm and cry when you have to take the remote out of my hands
- Turn and hide my head on your shoulder when I'm afraid of the pop-up toy
- Use an upset voice and scoot away when you're trying to put my shoes on

Self-Directed Learning

Understanding Messages

❑ I can use different actions and sounds that show I anticipate what will happen next.

- Roll over to you when you walk in the room to be near you
- Start pushing on my tray when I know it's time to get down from my highchair
- Scoot away quickly and giggle when I hear you say "Gonna get you"
- Cruise over and pull on your pants when I see you drumming on your lap
- Hold my arm out to help when you put my shirt on

Creating New Ideas

❑ I am interested in learning what I can do with objects.

- Explore your hair by rubbing and holding onto it while you carry me
- Bang a pot on the kitchen floor to hear the loud sound
- Splash my bath toys to see what will happen
- Drop cheerios on the floor and watch the dog come gobble them up
- Have fun smashing my banana on my tray

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SOCIAL COMMUNICATION™ GROWTH CHARTS

Milestones that Matter Most
23-24 months

Language

Gestures & Meanings

❑ I can use phrases that describe things and request new information.

- Use phrases to ask questions like *where daddy go* or what *doggie do*
- Say *what's that* to ask for the name of things
- Use phrases to describe things like *no touch hot, my shoe stuck,* or *my ball gone gone*
- Use words to describe locations like *up, out, in, off, on*
- Use phrases to deny or refute something like *no baby, not shoe, this ball not that one*

Sounds & Words

❑ I can use at least 100 words in phrases that include names, actions, and descriptions.

- Use phrases with agents and actions like *mommy kiss, doggie run, daddy throw, baby sleep*
- Use phrases to describe actions and objects like *car go fast, tree so big, truck loud, want red cup, put on table*
- Combine words that describe something not there like *grandma go home, no more home, blocks all gone*
- Use phrases with agents, actions, and objects like mommy kiss baby, kitty eat food, daddy push car, *mommy get bottle*
- Use phrases to solve problems and feel better like *ball stuck daddy*

Play

Using Actions with Objects

❑ I can combine several different pretend actions in a logical sequence.

- Put sand and stones in my dump truck, drive it over to the pretend building site, and dump it out.
- Give my toy bear a bottle, burp him, and then change his diaper
- Color an envelope and pretend to mail a letter by putting it in a shoebox
- Put my toy animals in a bucket, pretend to give them a bath, then dry them with a towel
- Pretend to wash my toy dishes, put them on a counter to dry, and then put them away

Social Sharing with Objects

❑ I can begin to take on a make-believe role in a pretend play scenario with you.

- Pretend to ride in a tractor and put our hats on while we're reading a book about the farm
- Pretend to serve you food and pour you a drink at our make-believe restaurant
- Pile up sofa cushions with you and pretend we are climbing a mountain
- Put boxes in my wagon and pretend we are at the grocery store, then pay you when I leave
- Pretend to be the doctor and listen to your heart while we play

Social Interaction

Social Attention

❑ I can talk with you about a topic I'm interested in like we're having a conversation.

- Start talking about the tree that fell down while on our walk together
- Point out and name the horses and cows I see while driving in the car
- Talk about the different balloons I see at the grocery store
- Ask what happened to the big pile of leaves we saw in the backyard
- Talk about what we can make with Playdoh today

Intentional Communication

❑ I can let you know how I feel and negotiate when things don't go my way.

- Tell you *Mad* and stomp my feet, when you ask me to put my favorite toy away
- Say *No leave Mimi* with a sad face when it's time to go home from visiting Grandma
- Say *One more time slide* when you tell me it's time to leave the park
- Help figure out what we can do together inside after hearing it's snowing and we can't go to the park
- Let you know I'm mad that you won't let me carry the eggs and instead ask to carry the apples

Emotional Regulation

Sharing & Managing Emotions

❑ I can use my words to share moments of success with you.

- Go to the drawer, find the ice cream scoop, and tell you *I got the big spoon*
- Say *My help* when I hold my foot up and step into my pajamas.
- Put my shoe on, close the Velcro strap, then look at you and say *Look, I do it*
- Say *Mommy watch this* when I squirt the hose and help water plants
- Say *Papa look* as I balance a box on my head

Regulating Challenging Moments

❑ I can calm myself down, come back to you, and communicate what I want or need.

- After getting upset when I'm told I can't have snack, I come back and ask if we can go outside
- Calm down and say *That's mine* after brother takes my favorite truck
- Run out of the room when you tell me it's time to go to bed and then bring you my favorite book
- Say *No-no* and stomp my feet when you don't give me my own snack bowl, but then say *Get my bowl*
- Say *My banana* and pout when you ask me to share with sister, but calm down when you say *Ask her to pour you milk*

Self-Directed Learner

Understanding Messages

❑ I can create opportunities to learn about things that interest me in everyday situations.

- Walk into the kitchen with my bare feet and tell you it's cold
- Ask you *Where they go* when the fireflies light up and then disappear while we search for them in the back yard
- Bring a worm I found in the garden, show you how it wiggles, and ask *Where him ears*
- Help Mommy make a smoothie then tell daddy what we put in it—*Banana, salad, and milk*
- Look at picture in book and say *Mommy book, Teddy bear make dough* and Mommy says *Like the cookie dough we made*

Creating New Ideas

❑ I can try out new things and seek out new opportunities for learning.

- Put on a raincoat and boots so we can take a walk and splash in puddles
- Help wash the car and lean how to spray with the hose to rinse
- Help find the bananas to put in my little cart while we go grocery shopping
- Find a pinecone outside and ask you what it is
- Climb through the new tunnel at the park and find you in the look-out window

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SOCIAL COMMUNICATION™ GROWTH CHARTS

Home About Guided Tour Get Started

Select Explore or Chart

EXPLORE

Learn the milestones.
Support your child's development.

Start Exploring

CHART

Watch your child grow.
Celebrate the small steps.

Start Charting

Explore Milestones By Age/Domain

9-10 Months | 11-12 Months | 13-14 Months | 15-16 Months | 17-18 Months | 19-20 Months | 21-22 Months | 23-24 Months

Language | Play | Social Interaction | Emotional Regulation | Self-Directed Learning

Examples of Social Interaction at 13-14 Months

Social Attention

Jase
Hailey
Aaron

I can watch you and imitate what you do and say.

Milestone | Support

Intentional Communication

Paul
Laina
Elias

I can communicate to share my enjoyment and interests with you.

Milestone | Support

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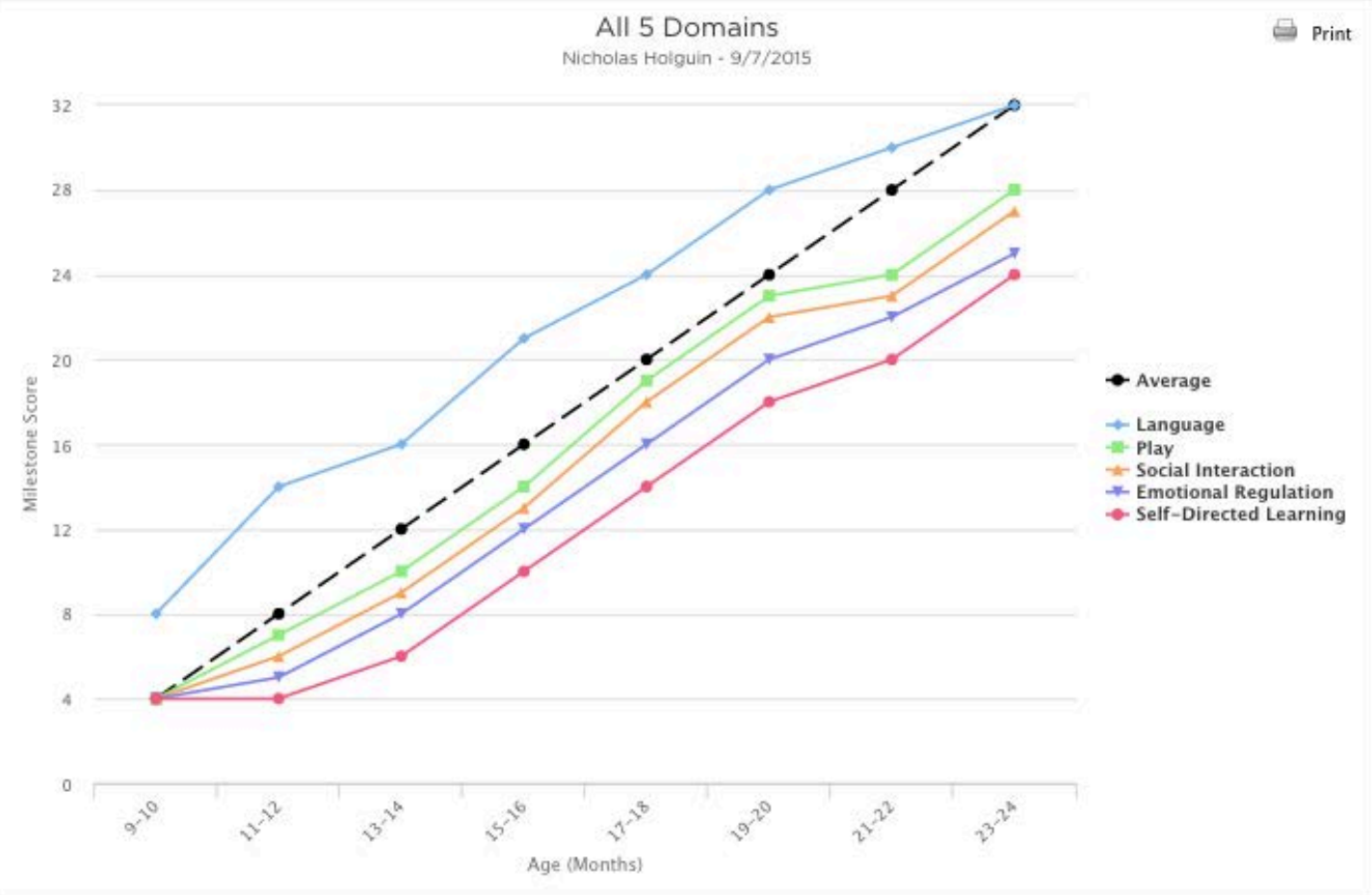
SOCIAL COMMUNICATION™ GROWTH CHARTS

Home About Guided Tour Get Started

Growth Charts for Nicholas

View all 5 domains or click to view each individual domain

All 5 Domains | Language | Play | Social Interaction | Emotional Regulation | Self-Directed Learning



SOCIAL COMMUNICATION™ GROWTH CHARTS

About | My Charts | FIRST WORDS® Project | Get Started

Language | Play | Social Interaction | Emotional Regulation | Self-Directed Learning | All 5 Domains

Language Milestones

Sounds & Words

Gestures & Meanings

SOCIAL COMMUNICATION™ GROWTH CHARTS

All 5 Domains

Brian-2014-06-25 (Age 19 Months)

March 11th, 2016

Language

Play

Social Interaction

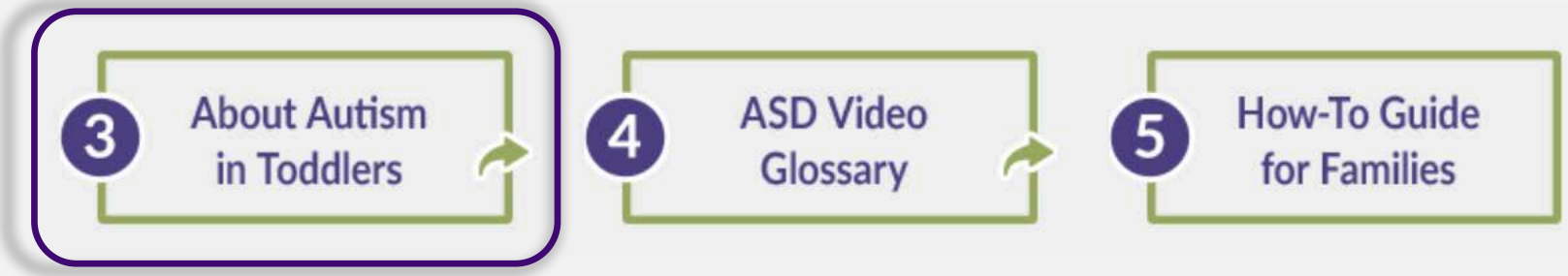
Emotional Regulation

Self-directed Learner

Seamless Path for Families

For all families

For families of children with a positive screen for autism



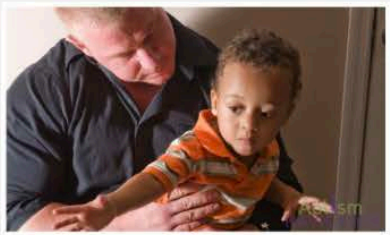
About Autism in Toddlers

- 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 PREVIEW

Courses for parents, professionals, 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 →

Autism NAVIGATOR®

About Autism in Toddlers

Autism NAVIGATOR®

About Autism in Toddlers

We are **10,000 Strong**

Urban Dictionary: Gathering of people ready to take on the world

- Launched April 2015
- Apr 2016: 3,643 unique users from 21 countries
- Oct 2016: 6,557 unique users from 103 countries
- Apr 2018: 13,100 unique users from 119 countries
- Oct 2018: 18,720 unique users from 120 countries

How many countries are there in the world?

We are reaching more than half of the world's 195 countries.

Welcome to About Autism

Select Language

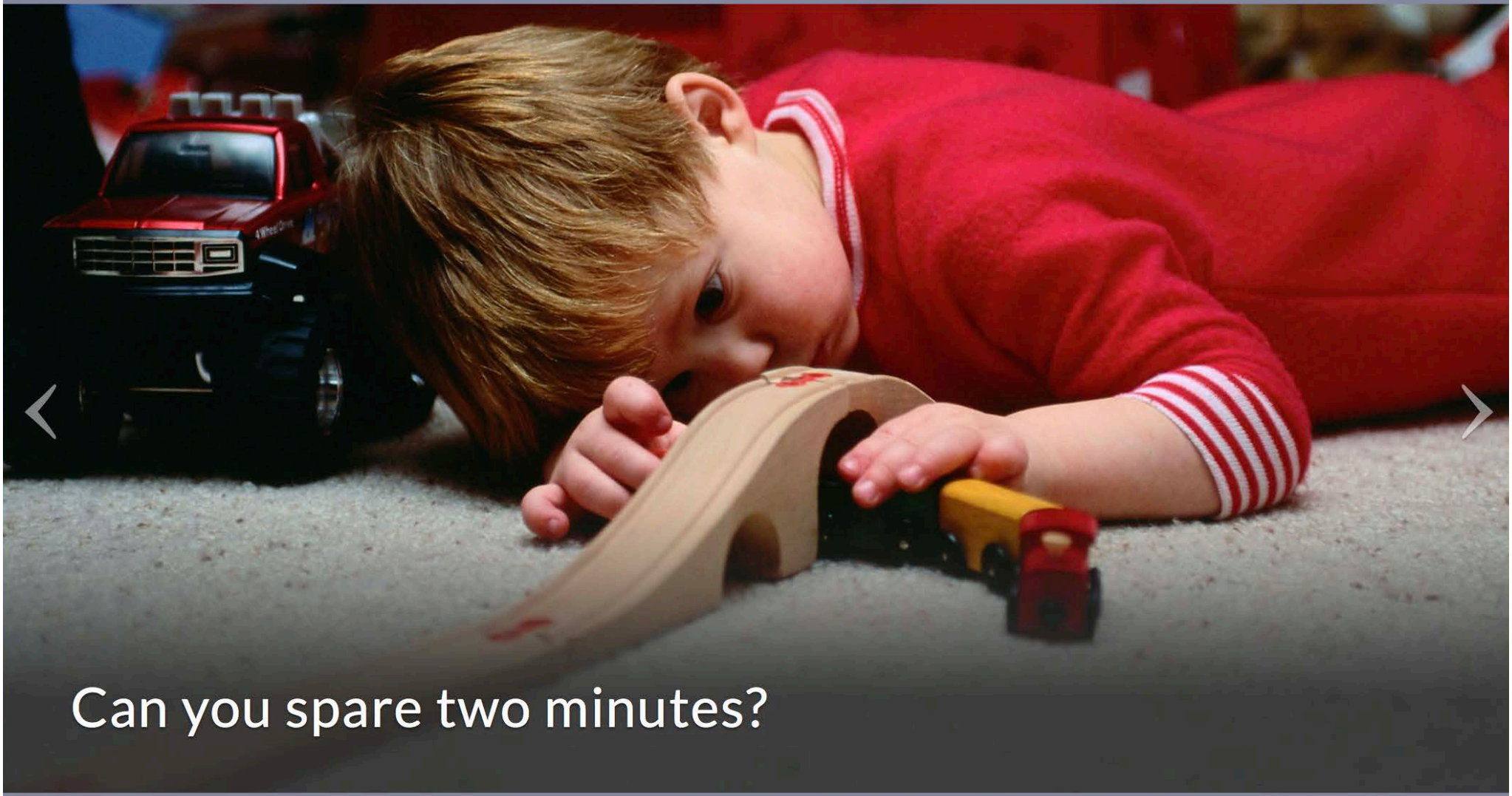
English

Start Presentation

Minimum System Requirements

- Operating System Recommended: Microsoft® Windows® 7; Mac OS X 10.6 or above; iOS 6.1.3 or above
- Browsers: Internet Explorer 10 or above; Firefox 20 or above; Chrome 6 or above; Safari 6 or above; Opera 12.5 or above
- 2 GB of RAM
- Screen resolution setting 1024 x 768 with 32 bit colors
- High Speed Internet connection required: DSL and/or Cable, 6Mbps and up (dial-up not supported)
- Video: Quicktime 7 or above; Browsers with HTML5 support
- Printable PDF: Adobe Reader 11 or above
- JavaScript and Cookies must be enabled
- Mouse, Keyboard, Speakers (if listening; monitor for Closed Captioning)

Autism NAVIGATOR® About Autism in Toddlers



Learn More

Autism NAVIGATOR About Autism in Toddlers

Home ASD Video Glossary Launch About Autism

Watch Now

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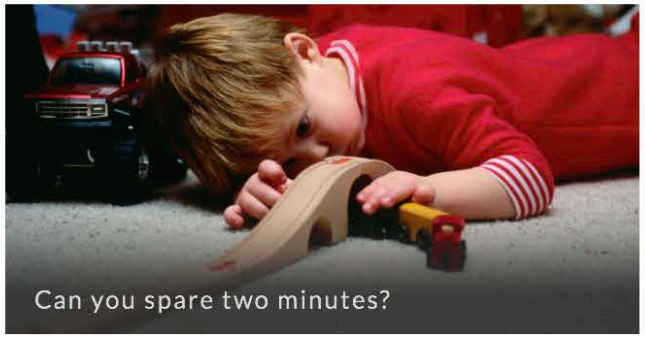
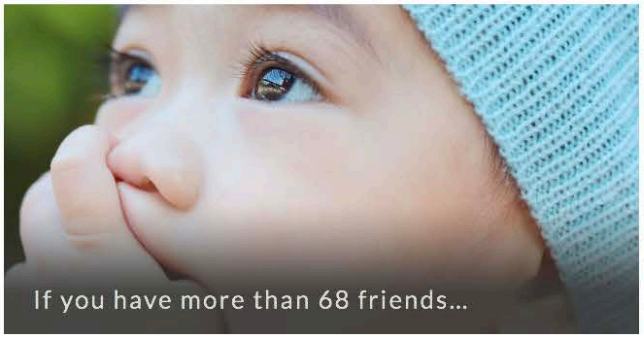
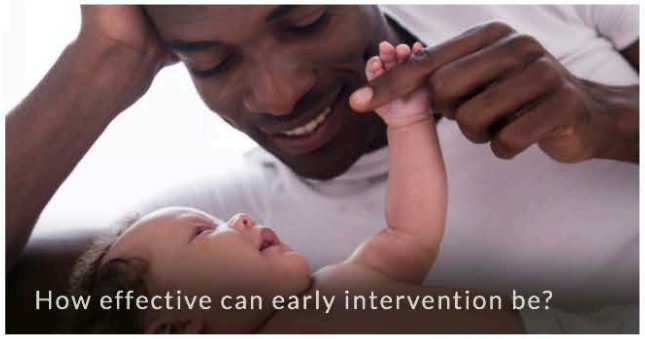
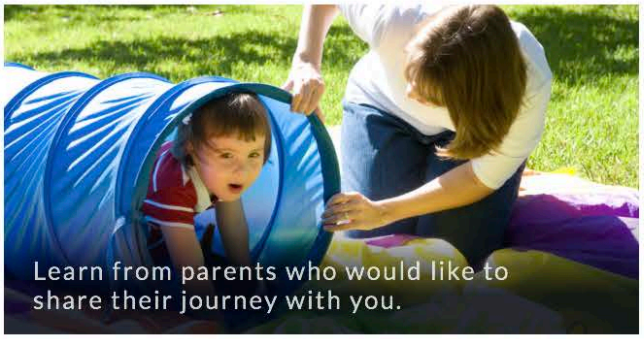
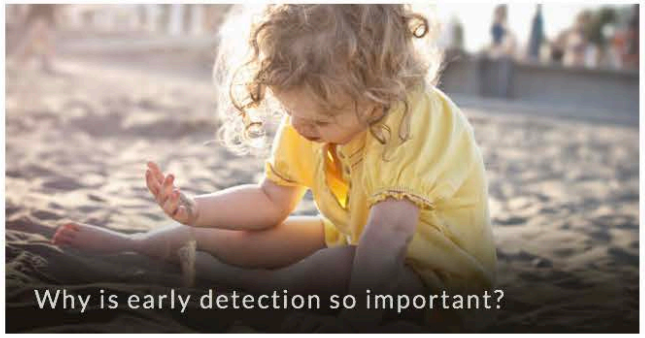
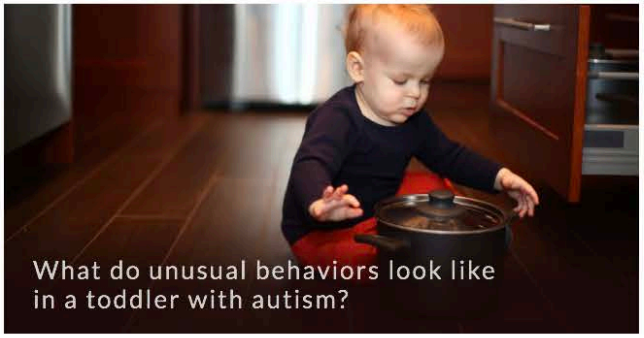












Critical Importance of Early Intervention

Early Signs of Autism

LB at 20 months

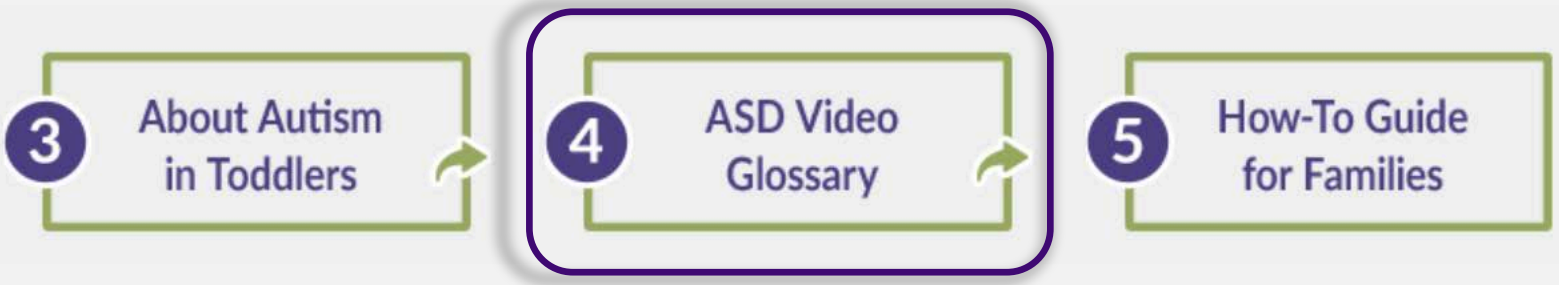
Change with Intervention

LB at 3-5 years

Seamless Path for Families

For all families

For families of children with a positive screen for autism



FIRST WORDS® PROJECT
FAMILY
E·CO·SYSTEM

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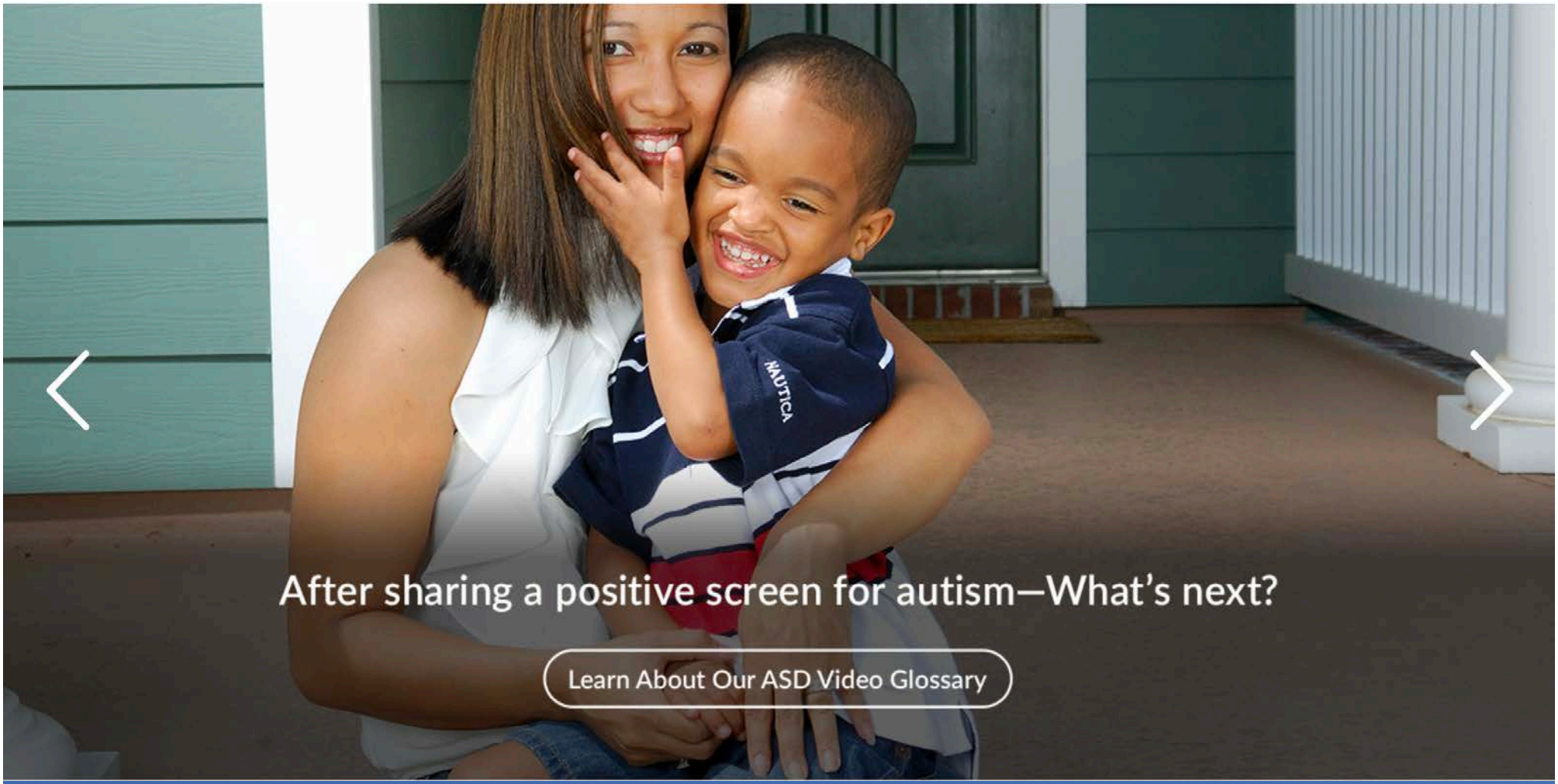
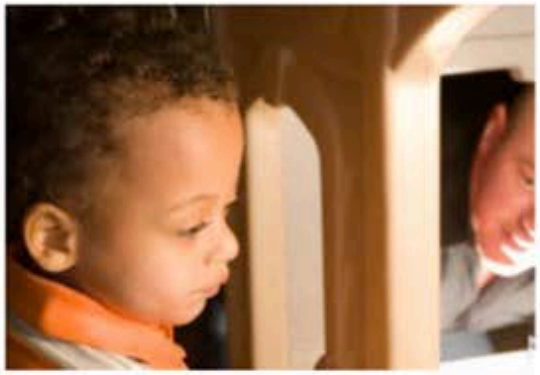


Autism NAVIGATOR

Return to Autism Navigator

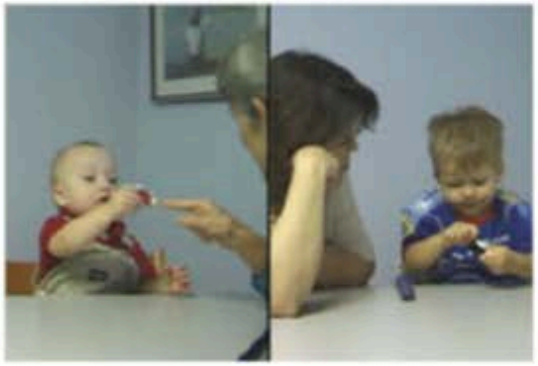
Welcome Amy Sign out



About Autism in Toddlers

Start here 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.

GET STARTED



ASD Video Glossary

For families and professionals who wish to **learn more** about the early signs of autism in toddlers. Uses side-by-side video clips showing behaviors that are typical in contrast with those that are red flags for autism.

GET STARTED

Social-Emotional Reciprocity

Initiating or Responding to Social Interaction

Initiating or responding to social interaction refers to a child's interest in being with and interacting with adults or other children by looking at them, smiling, and communicating in verbal and nonverbal ways. A typical child will show an interest in other children, and respond to, and initiate offers for interaction with adults and peers.

Typical

Jimmy at 15 Months

Jimmy is initiating and responding to social interaction with both his mom and the clinician. He shares his interest in the bubbles with his mom by looking at her, smiling, and showing her the bubbles.

Red Flags for ASD

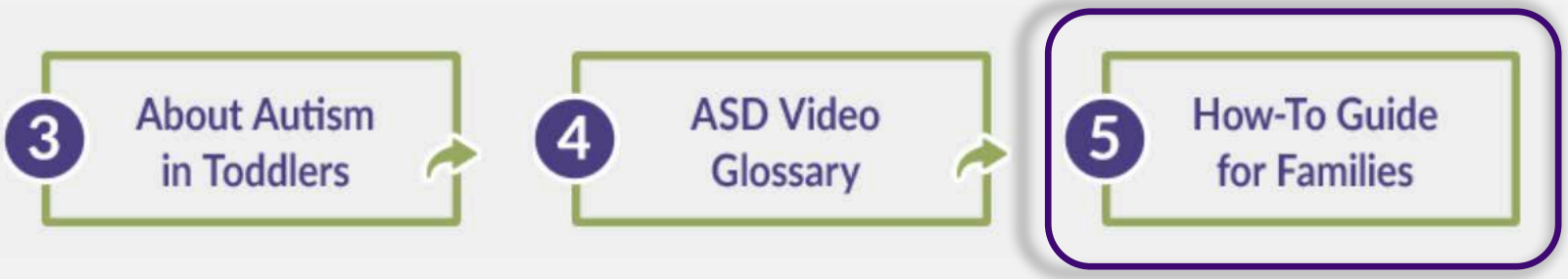
Ethan at 17 Months

Ethan is not responding to social interaction with either his mom or the clinician. Instead, he is overly focused on knocking down and rolling the jar.

Seamless Path for Families

For all families

For families of children with a positive screen for autism



5 Autism Navigator® — How-To Guide for Families

This interactive web-based course is for families who suspect their toddler has autism or a social communication delay. It will put in the hands of families hundreds of video illustrations of evidence-based intervention techniques you can implement in everyday activities to support your child's learning as soon as you suspect autism. This interactive program will teach families how to embed strategies and supports into everyday activities, provide developmental growth charts to help families recognize and monitor meaningful outcomes, and offer a video library to illustrate how to promote learning and development for toddlers with ASD. This How-To Guide for Families will also be instrumental for early intervention providers to use with families to improve outcomes of toddlers with ASD and their families.

LEARN MORE LEARN HOW TO ENROLL

Autism Navigator® How-To Guide for Families

About the Course

Course Audience

For families who suspect their child has ASD—get started right away to better understand how early signs of autism can impact development and learn how to use intervention strategies in everyday activities to support their child's learning and development.

Course Content

This interactive web-based course is for families who suspect their young child has autism or a social communication delay. It will put in the hands of families hundreds of video illustrations of evidence-based intervention techniques they can implement in everyday activities to support their child's learning as soon as they suspect autism.

This self-paced course has 7 hours of interactive slides and 5 hours of video libraries. The course will teach families how to embed strategies and supports into their everyday activities, provide developmental growth charts to help families recognize and monitor meaningful outcomes, and offer video libraries to illustrate how to promote learning and development for young children with ASD.

Autism Navigator How-To Guide for Families is comprised of 4 Guide Books and 2 Video Libraries:

- Guide Book 1: Social Communication Milestones and How Autism Impacts Development
- Guide Book 2: Collaborating to Make Early Intervention Work for You
- Guide Book 3: Getting Started with Early Intervention Right Away
- Guide Book 4: Addressing Challenging Behaviors
- Library of Change with Intervention
- Library of Everyday Activities

The Guide Books range from one to two hours of content for a total of 7 hours. We have developed the content to build across chapters in each book and across books. But you can decide what order you want to go through the slides, video players, and Guide Books, and how much of the content you want to complete. We hope you will return to the course later as a resource to watch more or to use the libraries when you need video examples as you are learning to support your child's development. Our e-learning platform includes a Tools section that has print documents to support your learning including a printed script of the content for each Guide Book that you can download.

This How-To Guide for Families will also be instrumental for early intervention providers to use with families they serve. It is designed as a companion course for families served by providers enrolled in the Autism Navigator for Early Intervention Providers Knowledge and Skills and Mastery Level courses. The content and video illustrations can help to maximize time for coaching during intervention sessions and improve outcomes of young children with ASD and their families. Families can use the Professional Directory available on www.AutismNavigator.com under Family Resources to find professionals who have completed Autism Navigator courses.

How to Enroll in the Course

You can learn how to enroll in Autism Navigator courses at AutismNavigator.com. Find Courses on the top menu and scroll down to see descriptions of the courses we offer and click on How to Enroll. You will be asked where you live so we can offer states or regions have group rates or sponsored seats available. Select Family Resources to learn about the free courses in our Seamless Path for Families.

Professionals with an annual subscription to Autism Navigator for Primary Care receive 20 seats in the How-To Guide for Families, a value of $625 per seat, to invite 20 families to complete the screen for autism who are ready to get started learning about their child's learning. Professionals with an annual subscription to Autism Navigator for Early Intervention receive 10 seats in the How-To Guide for Families to invite families who they are providing services to.

Families should ask their prior vention provider if they ar have any available seats fo purchase seats at www.A get started and their p seats available. Famili tism Navigator prof link to www.Autis about each cours

For individual and group pricing information, email sales@autismnavigator.com or call 1-844-427-345

It Takes a Team to Support Families

Autism Navigator courses and tools are designed to help support collaborative partnerships with the intervention system, community service providers, early care and learning, and families to improve child online platform maximizes the use of technology to bring evidence-based practice to families and com window of opportunity. Go to www.AutismNavigator.com to learn more about our courses and family

What You Will Learn from Autism Navigator® How-To Guide for Families

Guide Book 1: Social Communication Milestones and How Autism Impacts Development (2

- Key social communication milestones in infants and toddlers in 5 developmental domains:
  - ❑ Play — how young children learn and make connections with the physical world and how things work
  - ❑ Language — how young children become masters of interaction and communication first using gestures, soun sentences, generative language, and conversation
  - ❑ Social Interaction — how young children learn to share enjoyment, interests, ideas, feelings, and experiences to c in a balanced, reciprocal exchange
  - ❑ Emotional Regulation — how young children experience emotions, learn to regulate or manage their emotions refocus attention based on their emotions
  - ❑ Self-Directed Learning — how young children make connections between object, space and people, and develop strategies and creative and flexible thinking
- How the early signs of autism unfold and impact development and learning in these 5 developmental domains
- Importance of early gestures and what are the 16 gestures that all children should have by 16 months
- How to differentiate late bloomers from late talkers with persisting language problems
- Importance of preventing the secondary impact of autism on cognitive development and behavioral challenges and how t active engagement in young children with ASD

Guide Book 2: Collaborating to Make Early Intervention Work for You (1 hour)

- The critical role of the family in detecting the early signs of autism
- Family perspectives on learning their child may have autism and the impact on the family when early signs are missed
- Concerns about labeling a child and having difficult conversations about autism
- Professional perspectives on how to build consensus on the early signs and promote ongoing collaborations
- What are early intervention services and how a family can get started in early intervention and find resources

Guide Book 3: Getting Started with Early Intervention Right Away (2 hours)

- Why learning in everyday activities in the natural environment is so important to achieve the intensity needed for young children with AS
- How to create learning opportunities in everyday activities at home and in the community to give your child a home field advantage
- The components of active engagement to help you decide which targets are priority intervention outcomes for your child
- Evidence-based intervention supports you can use in everyday activities to promote active engagement that are organized into 3 layers like a layer cake

Guide Book 4: Addressing Challenging Behaviors (2 hours)

- Why children with autism have challenging behaviors
- How do you figure out the function of challenging behaviors
- How a positive behavior support plan can help your child

Library of Change with Intervention (2 hours)

- Library of edited video clips showing change with intervention from 18-36 months of age for 8 toddlers with ASD and their families

Library of Everyday Activities (3 hours)

- Library of 200 video clips of different families interacting with their toddlers with ASD in a variety of activities in each of the following 8 categories of everyday activities:

Play with People	Play with Props	Meals & Snacks	Caregiving
Play with Toys	Family Chores	Books, Letters, & Numbers	Transitions

Amy

Autism NAVIGATOR®

MY COURSES | ENROLL IN A COURSE | COURSE CATALOG | COURSE AUTHORS | CONTINUING EDUCATION | HELP

Autism Navigator How-To Guide for Families *(Incomplete)*

Change View | Exit

- Introduction to the Guide Books (Required)
- Questionnaire (Optional)
- Guide Book 1: Social Communication Milestones and How Autism Impacts Development
- Guide Book 2: Collaborating to Make Early Intervention Work for You
- Guide Book 3: Getting Started with Early Intervention Right Away
- Introduction to the Libraries
- Library of Change with Early Intervention
- Library of Everyday Activities

Autism Navigator® How-To Guide for Families
Online Guided Tour — for Families of Toddlers & Preschoolers

The *How-To Guide* (*H2G*) *Online Guided Tour* is for families who suspect their toddler or preschooler has ASD to help you support your child's development and learning. You are invited to participate in 24 weekly hour-long online guided discussions over 6 months. We are bringing this *Guided Tour* to you wherever you are.

The *H2G Guided Tour* is for families with young children up to 5 years old who are enrolled in the *Autism Navigator How-To Guide for Families* — a 12-hour, self-guided web-based course. A team of professionals will be your tour guide to walk you through each weekly online meeting. The *H2G Guided Tour* serves as a companion to the *How-To Guide for Families* web-based course — almost like a book club but more interactive. Families will see how the early signs of autism can impact their child's development. They will practice using intervention strategies in everyday activities to support their child's learning.

What will families get from *H2G Guided Tour*?

H2G Guided Tour is about connecting with other families, exchanging ideas and tips, and getting tools and training on how to support your child's learning and development. You will have an opportunity to meet other families with young children, who also show early red flags of ASD. By using video technology, it will feel like you are face-to-face with other families as you go through this journey together. During the weekly discussions, your tour guide will lead you through course content and provide opportunities for you to share information, ask questions, and practice what you are learning in the *How-To Guide*. You can participate from your smartphone, tablet, or computer.

Whether families suspect their child has ASD or are in the process of getting a diagnosis, the *How-To Guide for Families* online course, combined with the *Guided Tour*, provide the information and support you need to practice using intervention strategies to help your child. Families enjoy the weekly interaction and can stay in touch with other families they meet in the *Guided Tour*. When families are equipped with the tools and training they need, they are better able to support their child's success in school.

Who can participate in *H2G Guided Tour*?

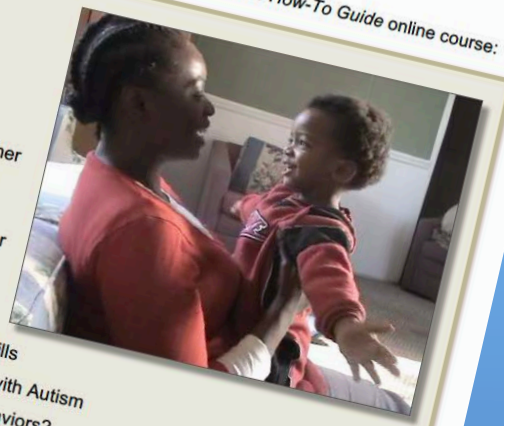
H2G Guided Tour is offered to one or two primary caregivers per family — parents, grandparents, and guardians — who have children 5 years old or younger. Space is limited to [illegible] group. Families need to be enrolled in Autism Navigator *How-To Guide for Families* course to participate in the *H2G Guided Tour* and we ask that you participate as much as you can from start to finish. Learn more about Autism Navigator *How-To Guide for Families* course, go to www.AutismNavigator.com

How do I access *H2G Guided Tour*?

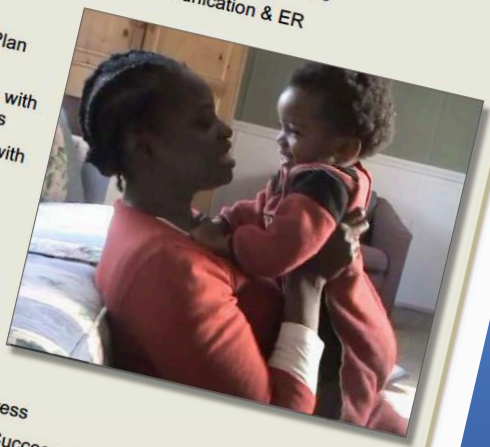
Families can access *H2G Guided Tour* from their smartphone, tablet, or computer. It works on the device you use, but good connectivity to the Internet is important. The better the connectivity, the better the conference in and watch videos with the group. We have a friendly team on hand to help. Our tour guides can offer a limited number of devices and Internet service for families in need. Contact us to learn more.

What are the Weekly Topics?

Following are weekly topics for the *H2G Guided Tour* organized around content in the *How-To Guide* online course:

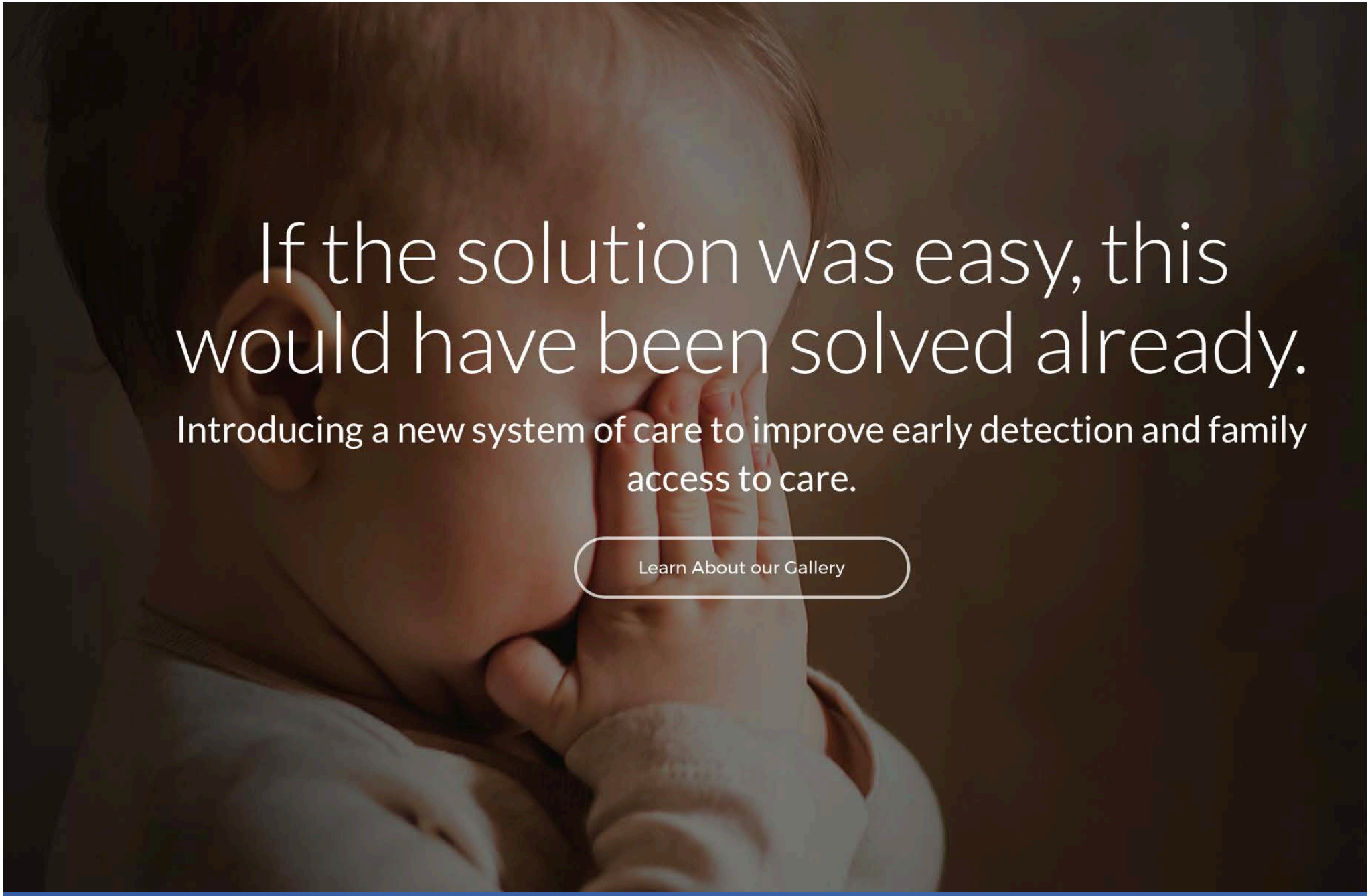


Week 1: Getting Started
Week 2: Autism and Development
Week 3: Taking Care of the Family
Week 4: The Home Field Advantage—Supporting Learning in Everyday Activities
Week 5: Active Engagement Step 1—Coming Together
Week 6: Layer 1 Supports for a Shared Agenda with Your Child
Week 7: Active Engagement Step 2—Keeping Together
Week 8: Layer 2 Supports for Reciprocity to Keep the Interaction Going
Week 9: Active Engagement Step 3—Working Together
Week 10: Layer 3 Supports to Teach Your Child Better Skills
Week 11: Recognizing Challenging Behaviors in Children with Autism
Week 12: Role of Emotional Regulation in Challenging Behaviors?
Week 13: Interplay of AE, TS, and Challenging Behavior: Hone Your Observation Skills
Week 14: Figure Out the Functions of Challenging Behaviors—Communication & ER
Week 15: The Functional Assessment Process is as Simple as A-B-C
Week 16: How Can a Positive Behavior Support Plan Help Your Child?
Week 17: Key Strategies and Supports for Children with ASD: Communication & ER Replacements
Week 18: Key Strategies and Supports for Children with ASD: Environmental Supports
Week 19: Intensity Needed to Achieve Meaningful Outcomes
Week 20: Supporting Transitions Between Activities
Week 21: Going Out to Everyday Places—Parks, Restaurants, Outings, Doctors, and More
Week 22: Better Skills to Get Ready for Childcare and Preschool
Week 23: Meaningful Outcomes—Keeping an Eye on Progress
Week 24: Using the Tools that you Have: Celebrating Your Success and Looking Ahead



It Takes a Team to Support Families

Autism Navigator interactive online platform maximizes the use of technology to bring evidence-based practice to families and communities at a critical window of opportunity. Go to www.AutismNavigator.com to learn more about our courses and family resources.



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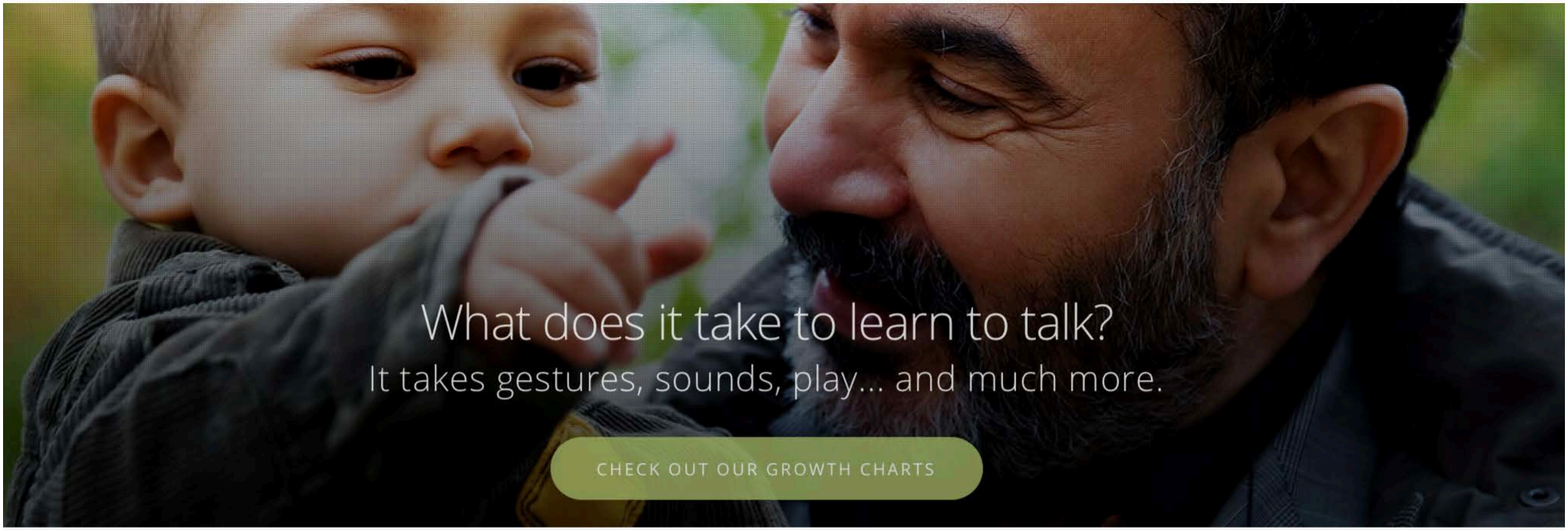
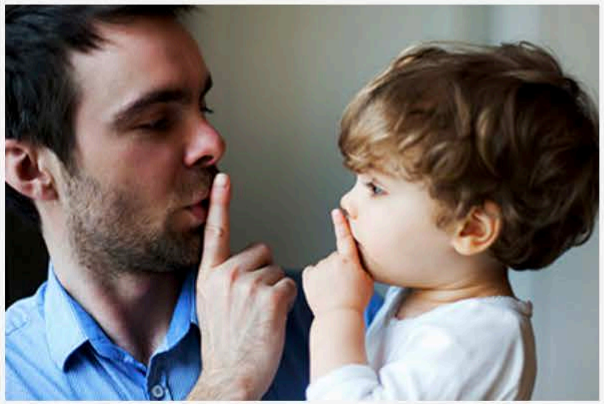




16 by 16 Series

Did you know that children should use at least 16 gestures by 16 months?

LEARN MORE

Growth Charts

Learn the Milestones in our Guided Tour for Families of Children 6-24 Months

FIND OUT HOW

Resources

Documents and Websites. Download. Print. Share.

VIEW RESOURCES

How can you screen for a communication delay in a child who can't talk yet?

- Infants and toddlers can be screened for skills that develop before children learn to talk, such as gestures, sounds, and actions with objects used in play.
- The Smart Early Screening for Autism and Communication Disorders (Smart ESAC) is a new online screening tool designed as a universal screen based on parent report for children 9 to 30 months of age.
- You will view a brief video before screening that explains the Smart ESAC and our Parent Portal.

All families screened with the Smart ESAC will have access to your child's results and much more on our Parent Portal.

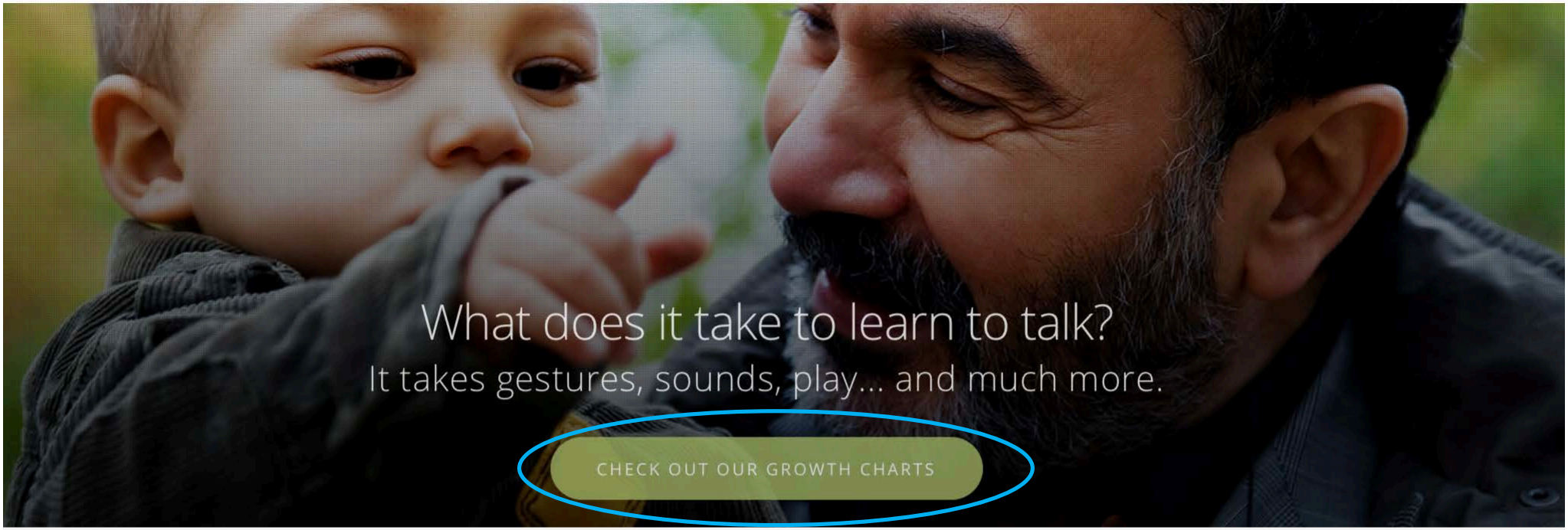
- Free access to the Social Communication Growth Charts.
- Screening reports & invitations to rescreen every 3-6 months.
- Links to resources in our Seamless Path for Families tailored to screening results.
- Monthly online check-ins to monitor next steps for your child.
- Invite your doctor or other service providers to view your portal to help build your care team to support you and your child.
- If your child's screening result shows a risk for autism, you will be invited to Autism Navigator courses and tools.

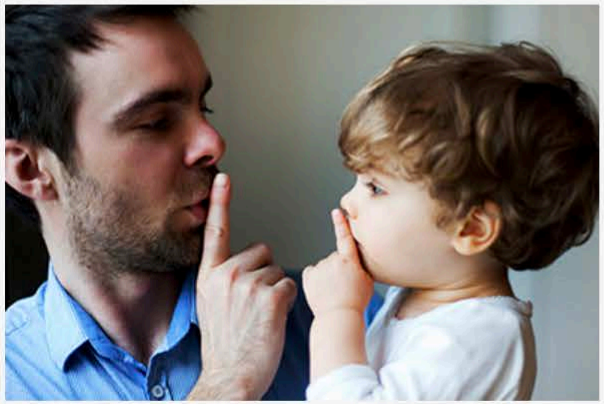
Autism NAVIGATOR®

Learn more at AutismNavigator.com.

If your child is between 9 and 18 months, we invite you to participate in our research and have your child screened with the Smart ESAC.

SCREEN MY CHILD





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SOCIAL COMMUNICATION™ GROWTH CHARTS

Membership | My Charts | FIRST WORDS® Project | About | Sign out

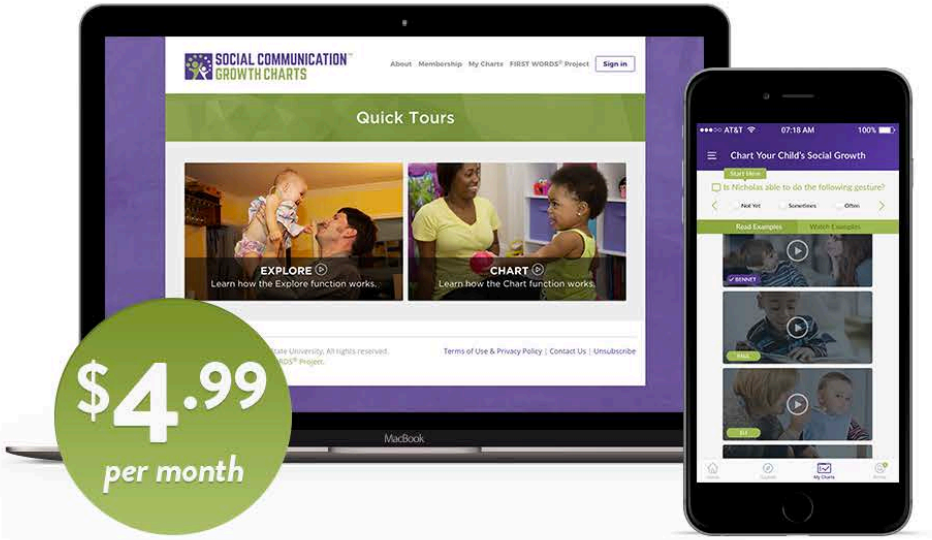
Babies learn at an amazing rate.
Learn the milestones that develop from 7 to 24 months.

Select your child's age.

7-8 | 9-10 | 11-12 | 13-14 | 15-16 | 17-18 | 19-20 | 21-22 | 23-24

Explore Hundreds of Videos. Chart Your Child's Growth.

How to Join



Buy Now | Join Free

Explore hundreds of video clips and Chart your child's development for up to five children.

- **The perfect tool.** For families of infants and toddlers 9 to 24 months of age.
- **Tool up.** A new way to learn the early social communication milestones. Just click on an age and watch hundreds of video clips of children learning. Answer a few questions each month and chart your child's social communication growth.
- **Tool around.** Learn how to take ordinary everyday moments and make them count.

SOCIAL COMMUNICATION™ GROWTH CHARTS

Membership | My Charts | FIRST WORDS® Project | About | Sign in

Two ways to get your membership FREE

- If your child is between 9 and 18 months old, you can participate in our research
- Answer questions online to screen your child for communication delay and autism with the Smart ESAC
- Receive a free membership to the Social Communication Growth Charts

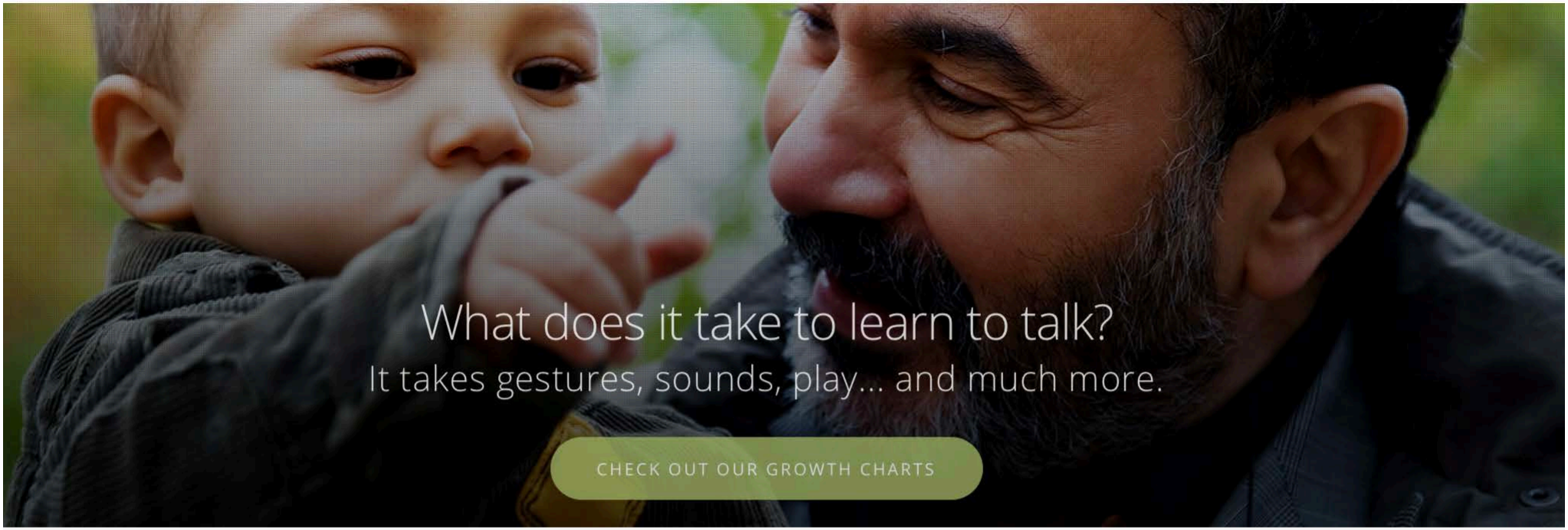
Get Started >

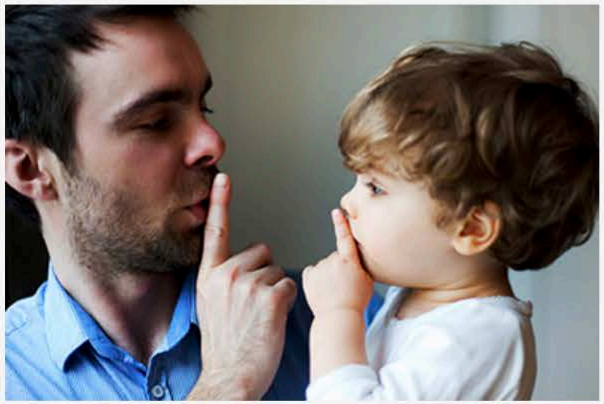
- Ask your provider if they can screen your child with the Smart ESAC
- Receive a free membership to the Social Communication Growth Charts
- Let your provider know the Smart ESAC is available to providers who complete the Autism Navigator for Primary Care

Learn About Autism Naviagtor Courses >

The American Academy of Pediatrics recommends screening all children for communication delay and autism. FIRST WORDS® Project can help you screen your child.

Learn More





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FIND OUT HOW

Resources

Documents and Websites. Download. Print. Share.

VIEW RESOURCES

Online Guided Tour for our Social Communication Growth Charts (SCGC)

About the SCGC Online Guided Tour

For families of infants and toddlers to learn about the milestones that matter most:

- An interactive online chat with other parents where a team of professionals will guide you through each meeting
- A companion series to the Social Communication Growth Charts
- Meet twice a month — to discuss how babies learn and the milestones that matter most
- Connect with other families of young children, share information, ask questions, and hone your observation skills watching videos

Learn how to support your child's development using strategies that will help prepare them early for preschool and kindergarten.

LEARN MORE

SOCIAL COMMUNICATION GROWTH CHARTS

Online Guided Tour
Milestones that Matter Most

The *Social Communication Growth Charts (SCGC) Online Guided Tour* is for families of infants and toddlers to learn about the milestones that matter most. Designed as a companion to the *Social Communication Growth Charts,* you are invited to join an interactive online chat with other parents where a team of professionals will guide you through each meeting — twice a month — to discuss how babies learn and the milestones that matter most. Connect with other families of young children, share information, ask questions, and hone your observation skills watching videos. Learn how to support your child's development using strategies that will help prepare them early for preschool and kindergarten.

About the *Social Communication™ Growth Charts*

The Social Communication Growth Charts is a powerful tool to help parents of infants and toddlers or anyone interested in young children to learn the critical milestones to launch language, learning, literacy, and much more by 24 months.

Each month, babies reach important new milestones — ***the ones that matter most*** are the ones they should reach before learning to talk. The most important learning begins with the interactions you share with your baby, taking turns and exchanging sounds, facial expressions, and gestures.

Explore the milestones — The **Explore** function lets you explore hundreds of video clips to learn the milestones in five domains of social communication development: language, play, social interaction, emotional regulation, and self-directed learning. Select one of the 5 domains and an age, every 2 months, from 7 to 24 months.

Each domain offers two developmental threads with side-by-side video players so you can see how milestones change and grow over time. Each Milestone video has a companion support video with commentary explaining how each parent or grandparent supports their child's learning in ordinary everyday moments, like bath time, diapering, feeding, dressing, and family chores.

Chart your child's social communication growth — The **Chart** function lets you chart your child's development after answering a series of questions. Then monitor which milestones they have reached, which are emerging, and which ones to look for in the coming weeks and months.

Everything you do and say matters. Especially during this critical period when your baby's brain is developing the most rapidly and is shaped by the experiences you provide. Catching communication and language delays early can prevent potential problems later with behavior, learning, reading, and social interaction.

Who can participate in the *SCGC Guided Tour?*

The *SCGC Guided Tour* is **free** for parents, grandparents, other family members, and guardians or caregivers who are caring for babies between 6 and 24 months of age. It is offered for three age groups:

- ❑ 6-12 months, *Before Words*
- ❑ 13-18 months, *First Words*
- ❑ 19-24 months, *Word Burst*

You can begin when your baby is 6 months or later, and move up to the next age group until your child's 2nd birthday.

Access Anywhere, Anytime

Explore, chart, and join the Guided Tour from your smartphone, tablet, or computer. It doesn't matter which platform you use, but good connectivity is important. We have a team on hand to provide technical support.

How to Enroll in the SCGC Guided Tour

Find out when the free Guided Tour series is offered and reserve your seat at **FirstWordsProject.com/SCGC-Tour**

Track Your Child's Growth and Celebrate Every Milestone Reached

Track 10 new milestones every 2 months in five developmental domains.

Language

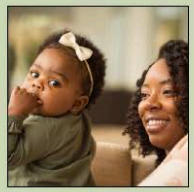
Discover how babies go from sounds, to words, to sentences in the first two years. Babies learn to use gestures like giving, reaching, waving, showing, and pointing. They babble, play with sounds, and learn from what they hear around them. This growing collection of gestures and sounds propels first words. By their first birthday, babies can say 1-2 words. They learn 1 new word each week until 18 months, when most can say 10-20 words. Then, like magic, babies begin learning a new word a day. By 24 months, they can use 100-200 words, and put together simple sentences.

Play

Discover how babies learn and make connections with the physical world and how things work. Babies are natural explorers. First, they explore objects by mouthing, banging, and dropping, then by using functional actions like pushing, turning over, scooping, pouring, and stacking. Learning what they can do with objects leads to pretending, and *that* launches imagination.

Social Interaction

Discover how babies learn to share enjoyment, interests, ideas, feelings, and experiences to connect with others in back-and-forth exchanges. Babies learn to use gestures, sounds, eye gaze, and facial expressions to get your attention and let you know what they want and don't want, how they feel, and what they're interested in. They are eager to interact—to share their experiences and ideas and listen to yours.



Emotional Regulation

Discover how babies learn to focus and refocus their attention and regulate or manage their emotions. Babies share their happy moments and sad or frustrated feelings. Learning to use actions, facial expressions, gestures, and words are crucial to learning how to manage emotions, so they can stick with necessary activities, flow with unexpected situations, and stay engaged in learning. These social communication skills make it easier to work through moments of frustration all babies face.

Self-Directed Learning

Discover how babies are active learners, make connections from their experiences, and become creative thinkers. Babies learn to watch and imitate what others do and say, which is essential to learning new words and actions. The words they hear help build vocabulary and inspire interest in learning. Their ability to imitate sparks a vocabulary burst and, as word learning explodes, they use words and phrases to describe, inquire, and negotiate with others. It is *this ability* to talk, imagine, and create new ideas that launches their drive for lifelong learning, and sets the stage for school success.

Everything you do and say matters. Learn how you can encourage milestones that matter most.
For more information about the *Social Communication Growth Charts*, visit www.FirstWordsProject.com.

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The SCGC Guided Tour is free for parents, grandparents, other family members, and guardians or caregivers who are caring for babies 6 to 24 months of age. It is offered for three age groups:

- 6-12 months, Before Words
- 13-18 months, First Words
- 19-24 months, Word Burst

You can begin when your baby is 6 months or older, and move up to the next age group until your child's 2nd birthday.

Access Anywhere, Anytime

Explore, chart, and join the Guided Tour from your smartphone, tablet, or computer. It doesn't matter which platform you use, but good connectivity is important. We have a team on hand to provide technical support.

How to Enroll in the SCGC Guided Tour

Our free Guided Tour is offered twice a month for an hour.

It is easy to register:

- Find your child's Age Group
- See the options of Days and Times—listed in Eastern Time Zone
- Select Register to enroll in the time slot that works for you and reserve your seat

SCGC Guided Tour Schedule — Reserve Your Seat Now

Age Group	Week / Day	Time*	
6-12 Months - Before Words	1st and 3rd Wednesdays	10am to 11am	Register
6-12 Months - Before Words	2nd and 4th Tuesdays	2pm to 3pm	Register
13-18 Months - First Words	1st and 3rd Thursdays	12pm to 1pm	Register
13-18 Months - First Words	2nd and 4th Wednesdays	2pm to 3pm	Register
19-24 Months - Word Burst	1st and 3rd Wednesdays	12pm to 1pm	Register
19-24 Months - Word Burst	2nd and 4th Thursdays	2pm to 3pm	Register

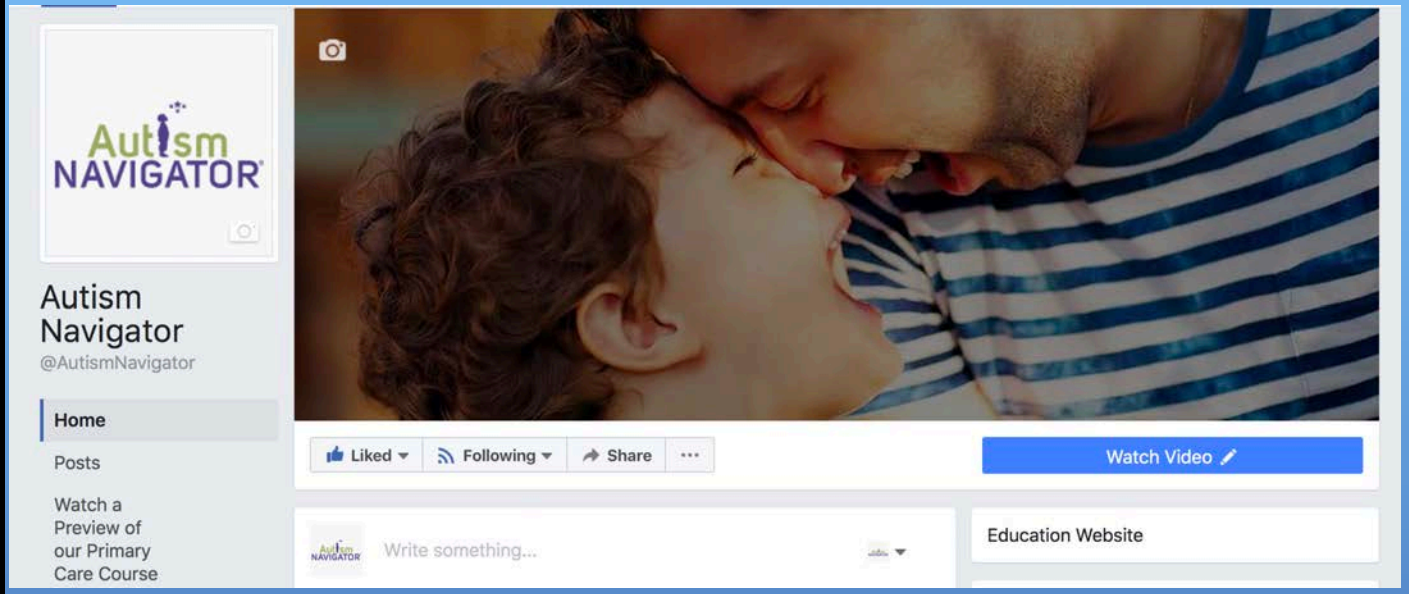
* Eastern Time Zone

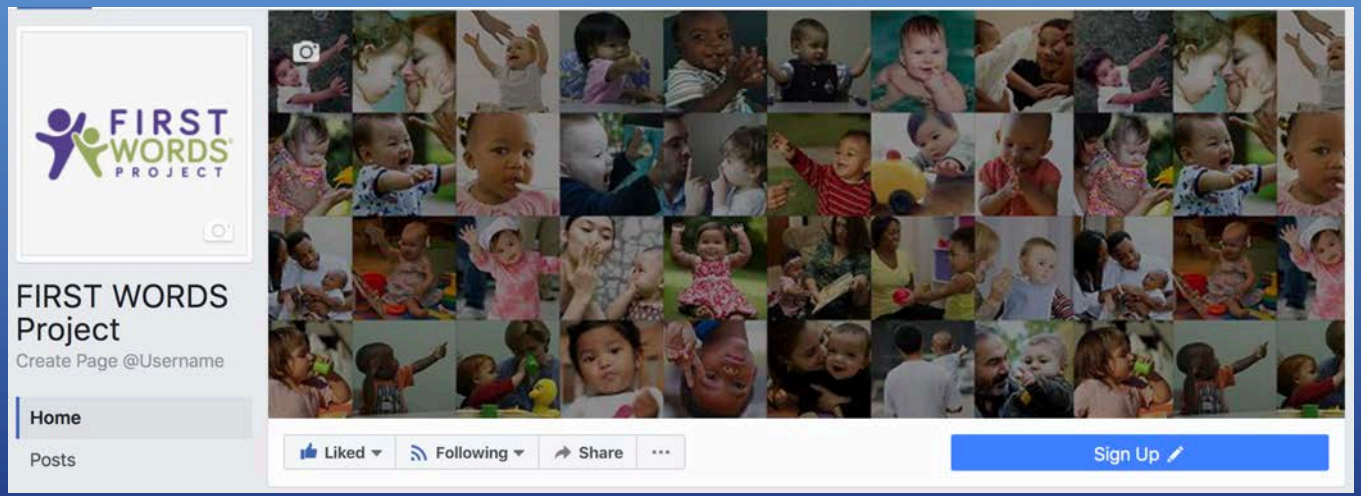
Everything you do and say matters. Learn how you can encourage milestones that matter most.

For more information about the Social Communication Growth Charts, visit scgc.firstwordsproject.com.

Learner Community

Like us and Follow us on Facebook





FIRST WORDS® PROJECT FAMILY E·CO·SYSTEM

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Thanks for your time!

Please help share our resources.

Multi-stage Screening in Part C Early Intervention to Address Health Disparities in Age of ASD Diagnosis and Service Receipt

Alice S. Carter, Ph.D.
University of Massachusetts Boston

IACC Presentation

January 17, 2018

Collaborators: Work that Takes a Village

Current Work:

- **R. Chris Sheldrick, Ph.D. (Dual PI)**
- **Abbey Eisenhower, Ph.D.**
- Angel Fettig, Ph.D.
- James Benneyan, Ph.D.
- **Thomas Mackey, Ph.D.**
- **Frances Martinez Pedraza, Ph.D.**
- Ivy Giserman Kiss, M.A.
- Elizabeth Frenette, M.A.

ITSEA & BITSEA Development:

- Margaret Briggs-Gowan, Ph.D.

Health Beliefs Framework:

- Nicholas Mian, Ph.D.
- Leandra Godoy, Ph.D.

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Funding Acknowledgements / Financial Conflicts

- National Institute of Mental Health (NIMH, R01MH104400)
- Department of Health and Human Services, Health Resources and Services Administration (HRSA, R40MC26195)
- Autism Speaks Weatherstone Fellowship to Frances Martinez-Pedraza

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Goals of Presentation

- Describe our current NIMH ASD PEDS network implementation and dissemination screening study and some preliminary findings
- Discuss some implications of understanding screening as a process rather than an event.

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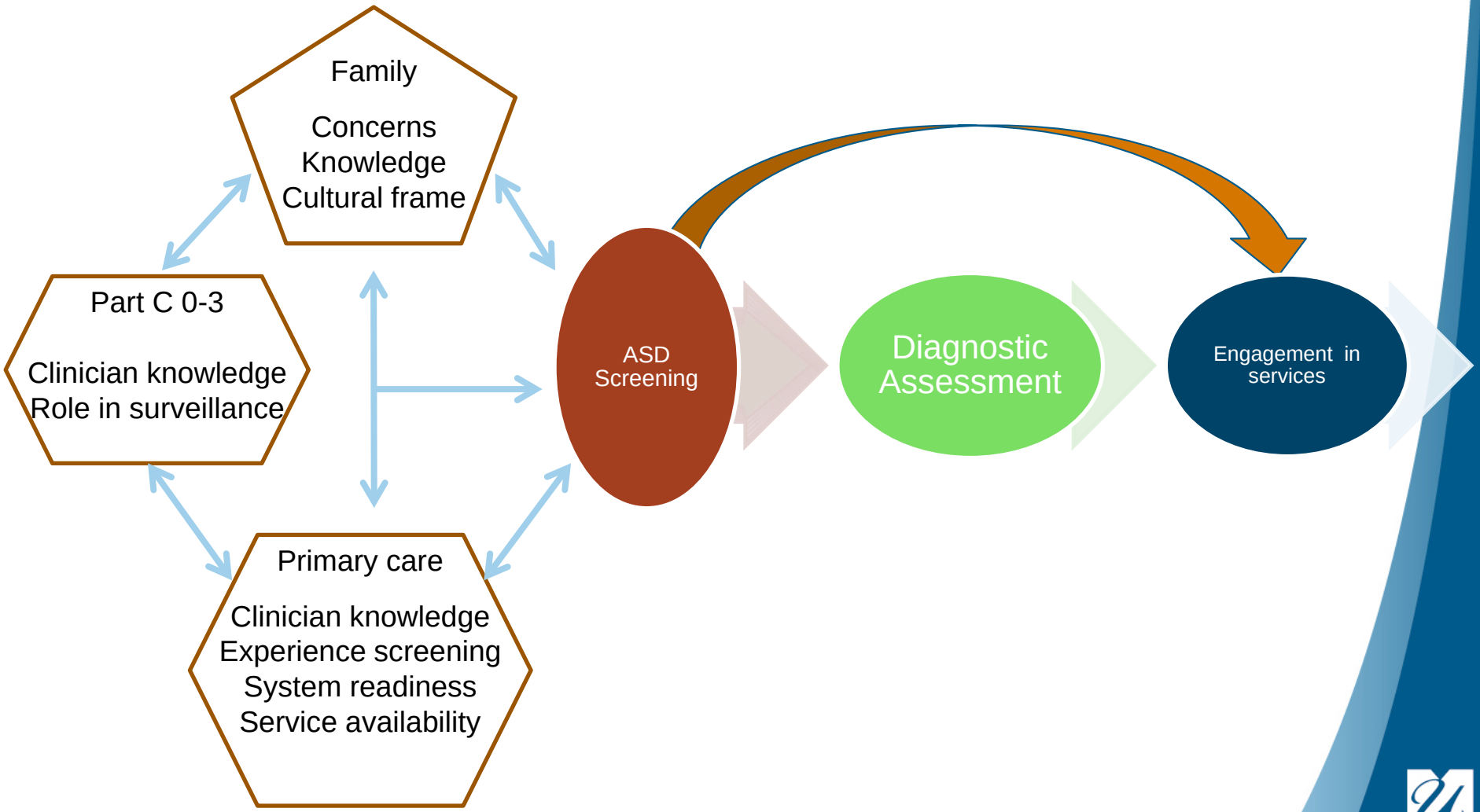
Unpacking ASD Screening Across the ASD PEDS Network



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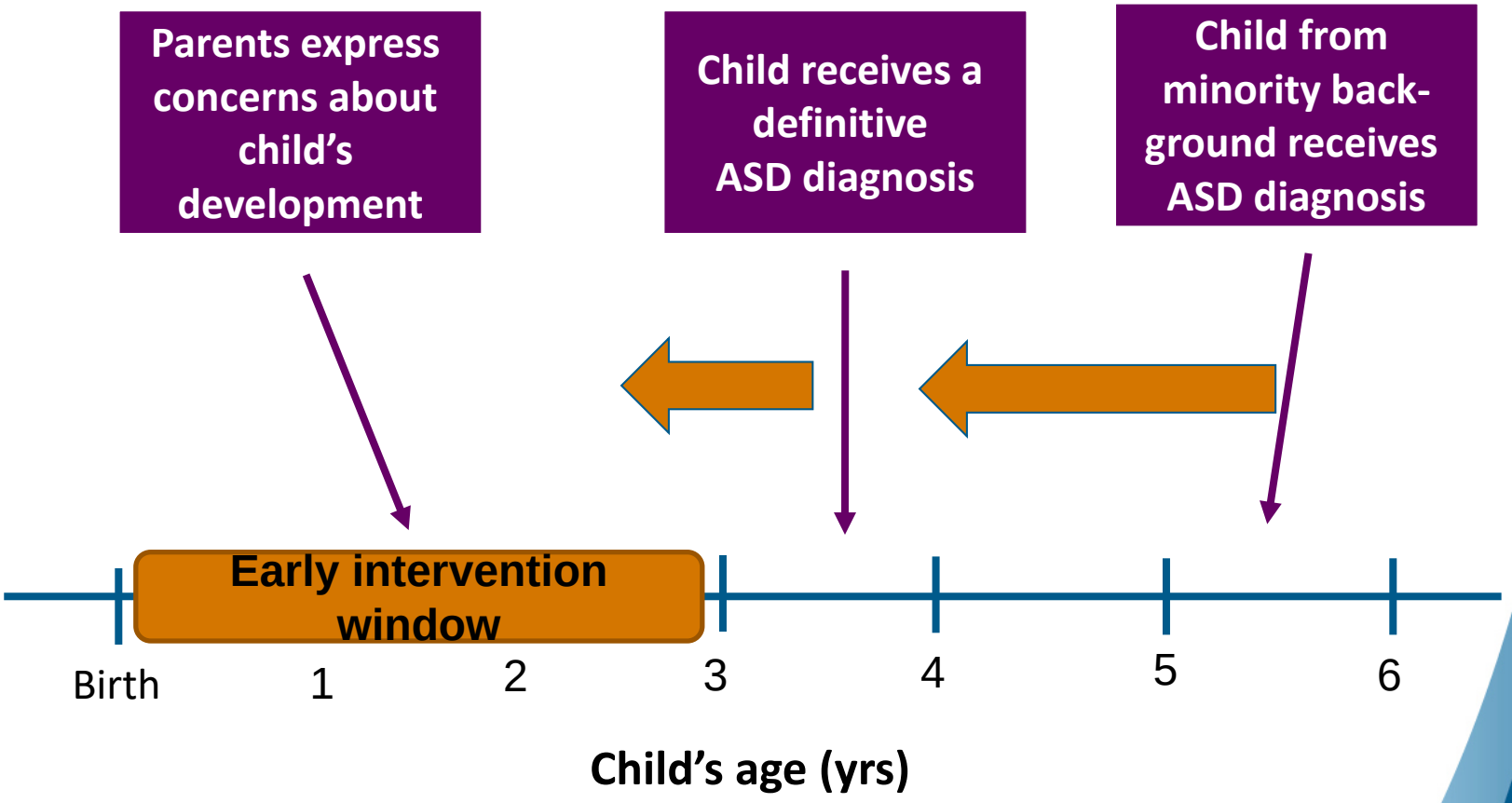
The diagnostic timeline

Long delays between first concerns and ASD diagnosis



Background

- **Health Disparity:**
  - **A particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage (USDHHS, 2010)**
  - **A chain of events signified by a difference in environment, access to, utilization of, and quality of care, health status, or a particular health outcome that deserves scrutiny (Carter-Pokras & Bacquet, 2002)**

- In Massachusetts, there were disparities in age at ASD diagnosis among children whose families had already accessed Part C early intervention.

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Health Disparities: Contributing Factors

External family-level contributing factors:

- **Language, insurance status, transportation, immigration status, child-care setting (family versus center-based);**

Internal family-level factors:

- **Efficacy expectations, trust in providers, fear of being blamed, knowledge and beliefs about services and child development;**

External Clinic- and provider-level factors:

- **Hours of operation, cost, workforce diversity;**
- **Untested sensitivity or specificity of screening measures**

Internal Clinic- and provider-level factors:

- **Negative or mistaken perceptions, efficacy expectations regarding screening and intervention (e.g., “too young,” “wait and see,” “chaotic family,” too much for family at this time)**

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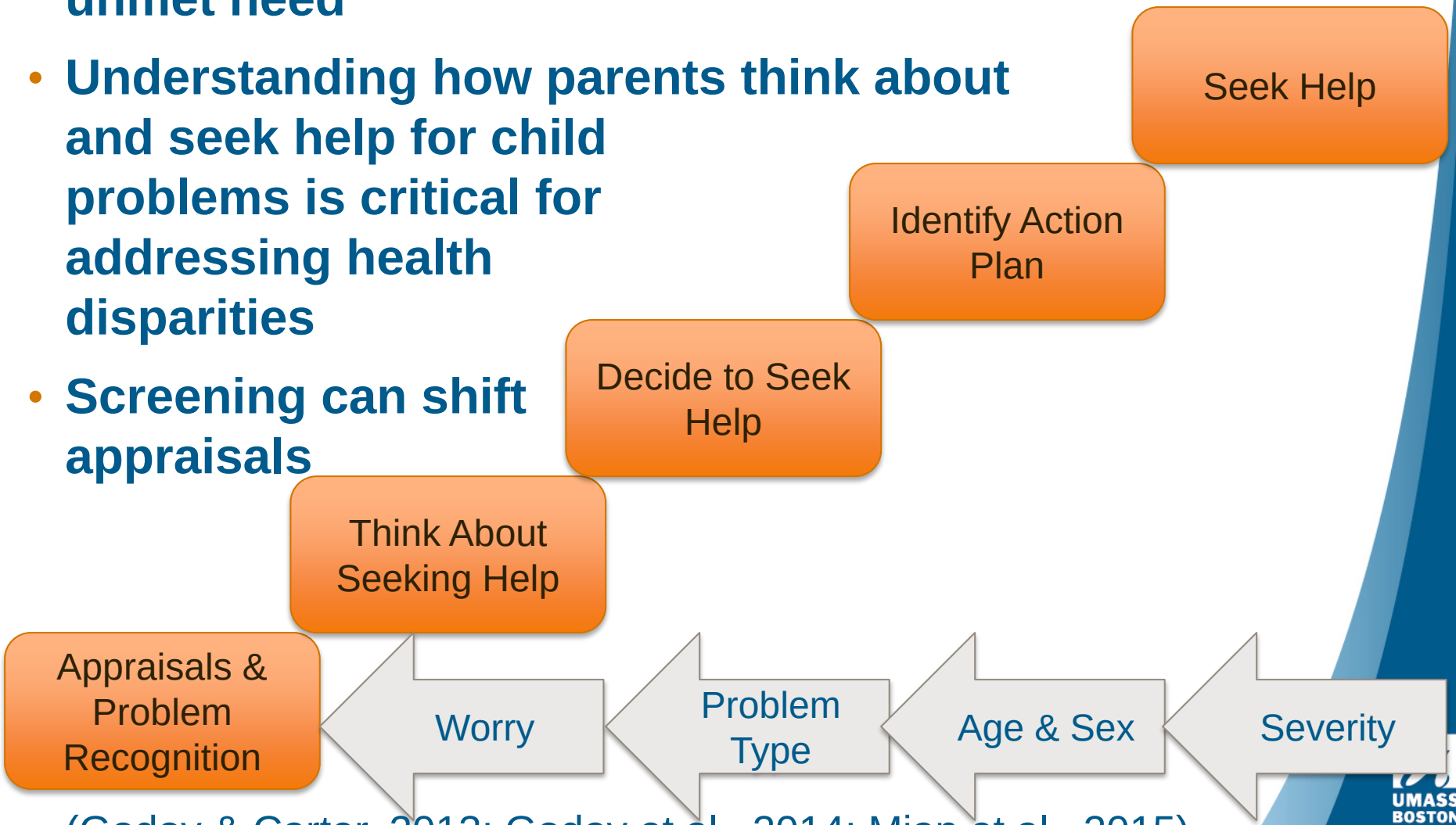
Parent Appraisals & Help Seeking Models: Applied to the Screening Context

- **Parents are critical agents in efforts to reduce unmet need**
- **Understanding how parents think about and seek help for child problems is critical for addressing health disparities**
- **Screening can shift appraisals**



(Godoy & Carter, 2013; Godoy et al., 2014; Mian et al., 2015)

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Overarching Goals of ABCD Early Screening

- Evaluating systems of care versus individual measures
  - Can disseminating enhanced, multi-stage, broad-band screening in Part C Early Intervention reduce health disparities in:
    a) Early detection and diagnosis of ASD
    b) Receipt of tailored intervention services &
    c) Improve developmental outcomes for ALL children and families
  - We are using mixed methods, health systems engineering methods to aid in monitoring fidelity of implementation, conducting cost analyses, and developing simulation models for testing hypotheses.
  - We are focusing on a screening process.

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ABCD Early Screening Project

- A Part C Early Intervention (EI) - centered multi-stage, screening and assessment protocol, offered in both English and Spanish
- Conducted in partnership with three EI agencies – multi-stage screening occurs within the context of routine clinical practice
- Goal: Targeted universal screening of all EI clients
- Standardized, evidence-based measures
- Builds on existing family- EI provider relationships
- Using technology for training and enhancing screening

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Phase I: Screening Process

Stage 1: Screening Questionnaires (Everyone 14-33 months)

Parent Report (POSI and BITSEA)

EI Provider Concerns

Parent Concerns

Stage 2: Observational Screening (Everyone positive at Level 1)

Screening Tool for Autism in Toddlers & Young Children (STAT)

Stage 3: Diagnostic Assessment (Everyone positive at Level 2)

Autism Diagnostic Obs. Sched.-2 (ADOS-2)

Mullen Scales of Early Learning

Parent Interview, Vineland Adaptive Behavior Scales III

Boston Promise Initiative

Screening Population: Who is Served by Our EI Agencies?

Circle of Promise

- a 5-mile geographic zone of Boston designed by the Mayor's Office
- 165,005 residents
- 76% of children are low-income,
- 55% of adult residents have high school-level education or less,
- median household income of ~$40,000 is $10,000 < citywide.
- 98% are children of color
- 47% English language learners

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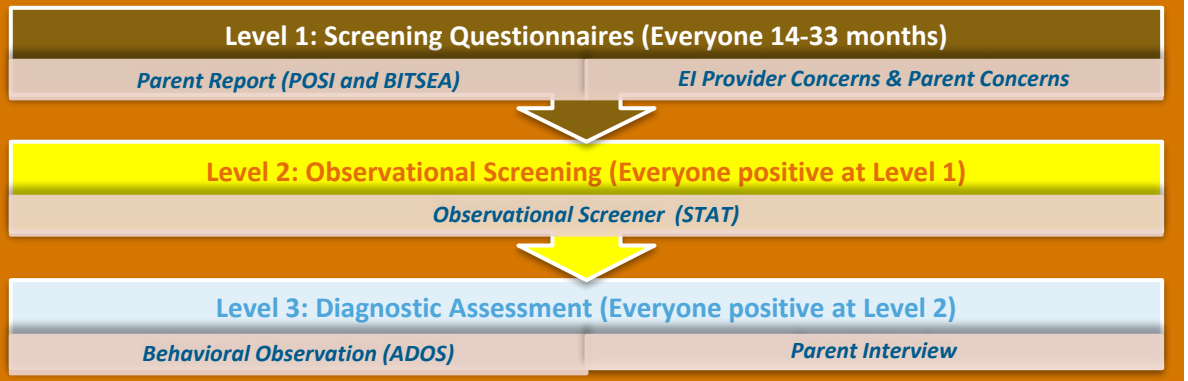
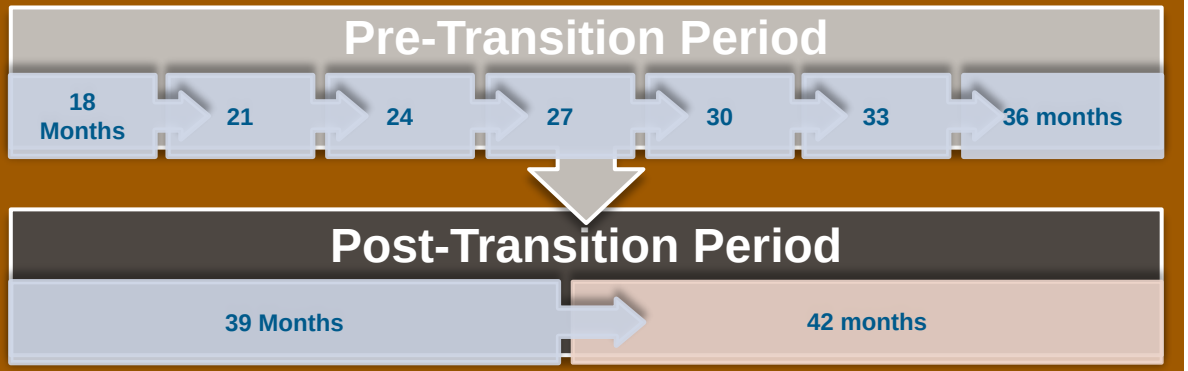
Phase I

Screening & Assessment Protocol



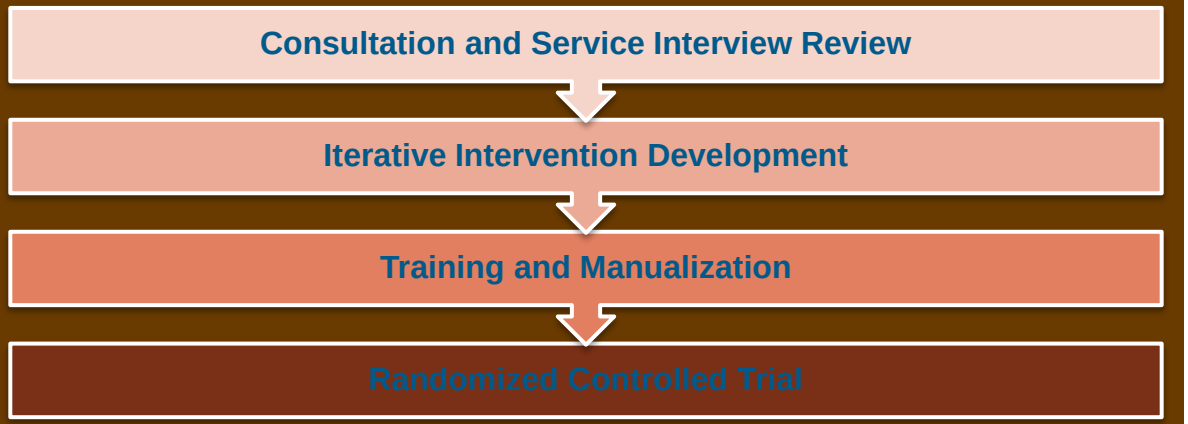
Phase II

Service Utilization Interviews



Phase III

Motivational Interviewing Intervention



Multi-Stage Screening & Diagnostic Assessment:
EI Provider (EIP) Participation & Building Capacity

Pre-Phase I & Ongoing: Impact on EI Workforce

- ✓ Training of EIPs in the Stages 1 & 2 screening protocol

~160 EIPs trained in the Stage 1 screening process	~32 EIPs trained in the Stage 2 STAT	94 EIPs have attended a diagnostic assessment

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Phase 1: Multi-Stage Screening & Diagnostic Assessment

Support for Difficult Conversations is Needed

Early Intervention Providers (EIP) tell us they are uncomfortable raising their concerns about ASD with parents and at itmes choose to delay suggesting further screening.

→ developed formal training for EIPs in how to raise concerns with families.

→ resources (web-based guide, “scripts” for parent-EIP conversations at each stage of screening)

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Phase 1: Multi-Stage Screening & Diagnostic Assessment

- **The screening process facilitates opening conversations about ASD risk with parents**
  - **In about half of our screened families, when an EIP is concerned and parents are NOT concerned, the parents have endorsed *red flag* behaviors and screened positive on the BITSEA and/or POSI.**
  - **Knowing whether the parent is concerned facilitates the conversation.**
  - **EIPs and parents can "wonder together" about the behaviors on the BITSEA/POSI.**

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Retention, Positive Screens, and Diagnoses: Room for Improvement

STAGE 1

Total Children Screened ~2800

~70 % screened

~35-40% of Children Screen Positive

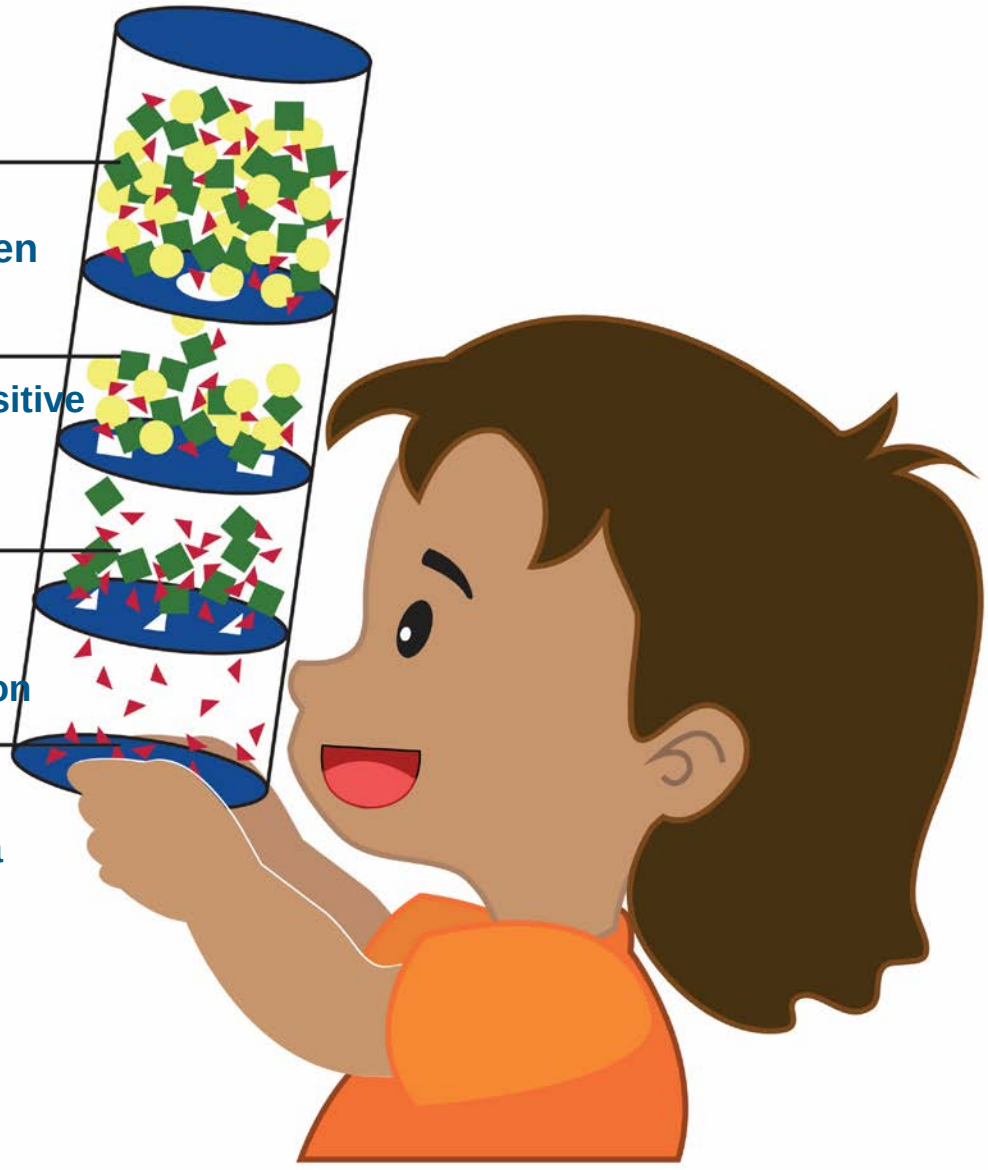
STAGE 2

~70% of Screen Positive get Stage 2 (STAT); ~70% assessed are positive on Stage 2

STAGE 3

~90% of Stage 2 positive receive a diagnostic evaluation

~85% of those evaluated receive a diagnosis of ASD



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Results: What can we learn from our screening and assessment rates?

Overall ASD prevalence within EI:

- Our overall rate of ASD diagnosis is just over 10% Given that the rate of previously-diagnosed children in EI was ~2.5%, **this suggests that the total prevalence of ASD in this EI population is approaching 13 percent.**

Reducing health disparities in detection:

- The sample reflects high rates of racial minority, linguistic minority, and low-income statuses.
  - The children we diagnose have higher rates of ELL status and low-income status than the previously-diagnosed children.
  - We seem to be identifying children from groups that are typically missed or diagnosed later.

Feasibility and Sustainability:

- The high rates of screening and overall compliance with the process suggests that this approach is feasible and sustainable.
- We can improve further by helping EIPs feel more comfortable with the later stages of screening.

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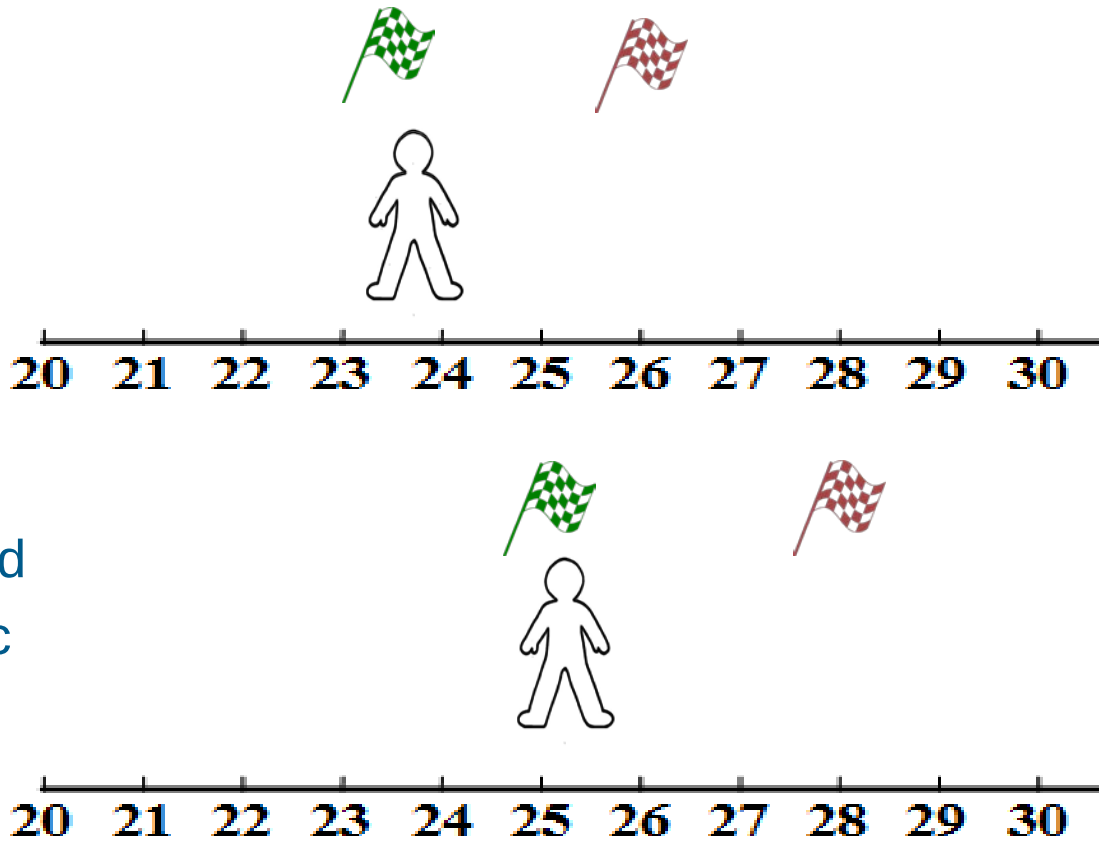
Is Race a Factor in Screening Process Timing?

White,
Non-Hispanic

Non-White, and
White Hispanic



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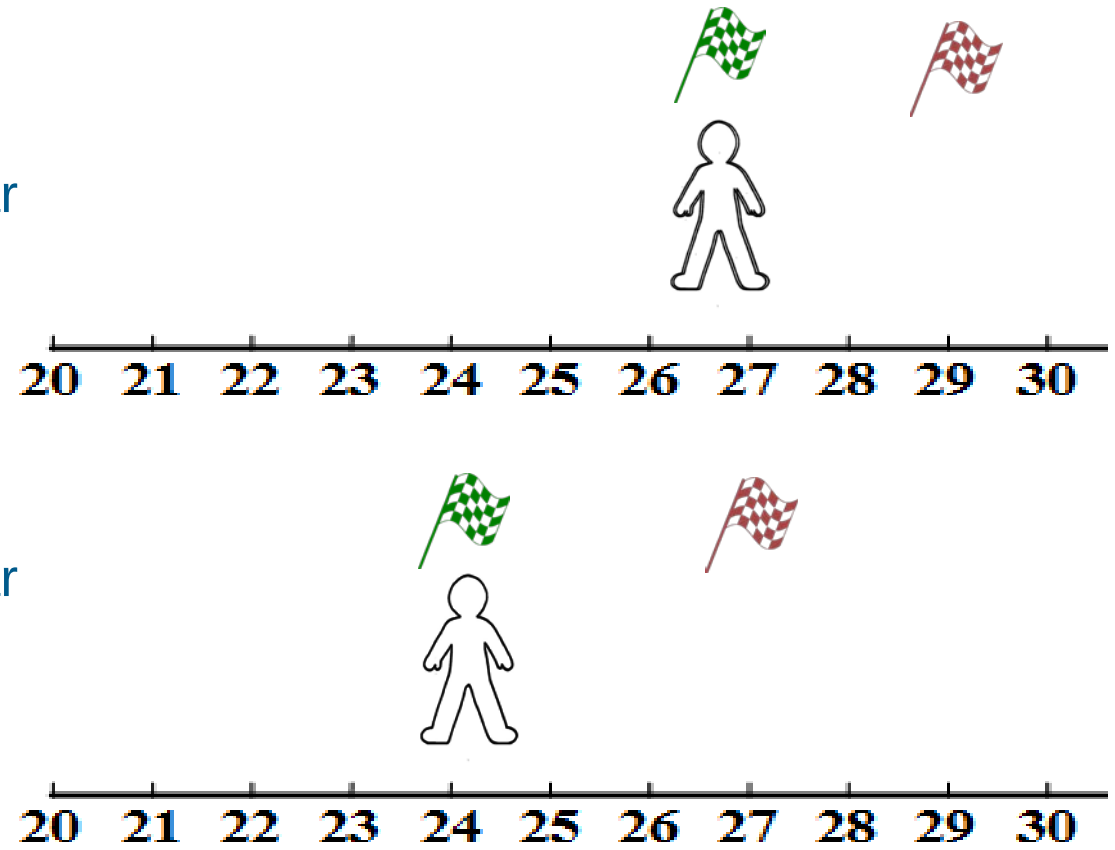
Is Income a Factor in Screening Process Timing?

> $45,000/year

< $45,000/year



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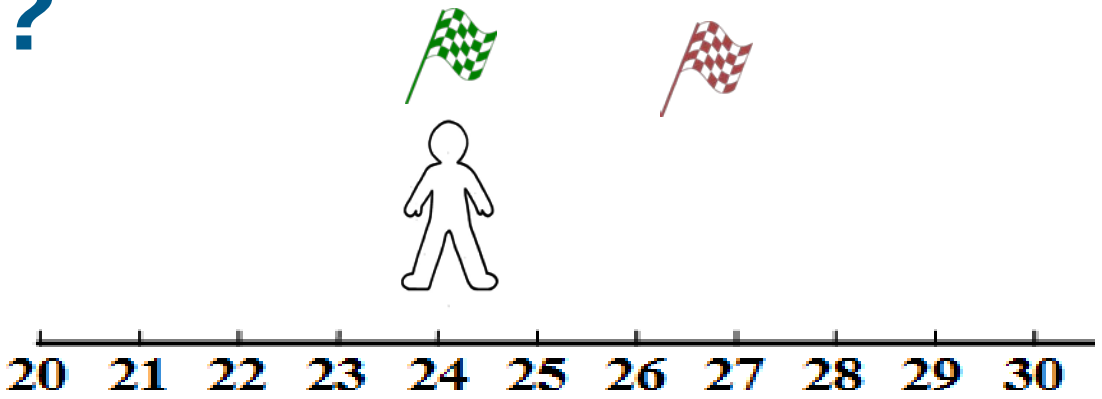
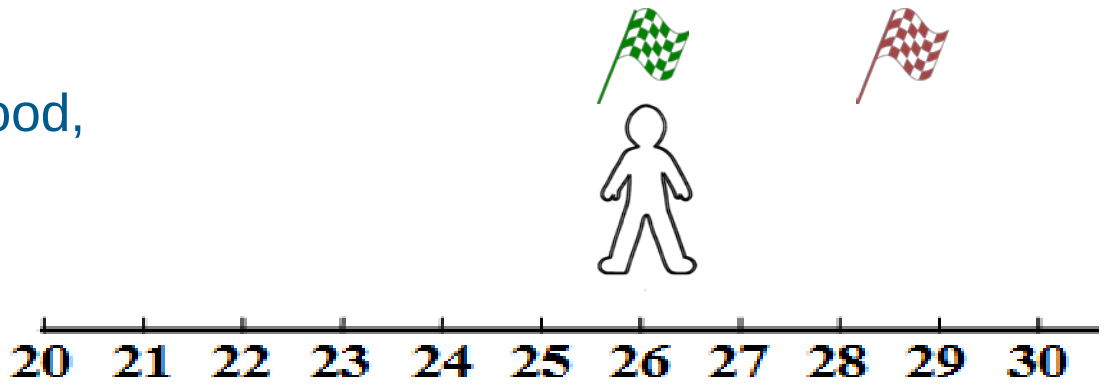
Is English Language Proficiency a Factor in Screening Process Timing?

Excellent



Very Good, Good, Fair or Poor



Months

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Phase I

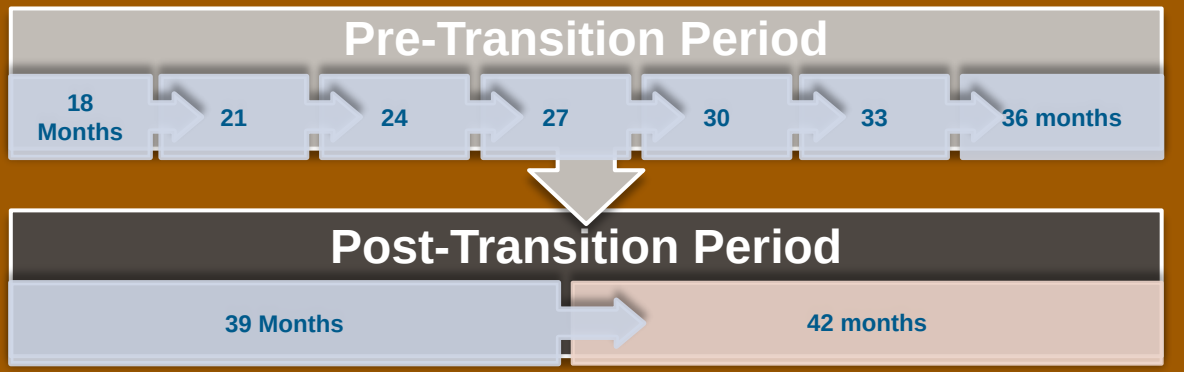
Screening

& Assessment Protocol

Phase II

Service Utilization

Interviews



Phase III

Motivational Interviewing

Intervention

Service Utilization

- EI Part C Service Utilization (pre-transition):

~80% are receiving high-intensity, ASD-Specific services

On average, time from ASD diagnosis to start of high-intensity services is ~2 months

- School-Based Service Utilization (post-transition)

~80% in school (most in public school)

~80% receive special education services

Very few ~10% receive non-school services

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Service Utilization Interviews: Preliminary Results in Relation to Health Disparities

- Pre-transition: Who is receiving high-intensity EI services?
  - **Race: ~90% of white children and ~70% of children of color**
  - **Language: ~90% of English speakers and ~55% of English language learners**
  - **Income: 95% of those with income >$45,000 and 73% of those with income <$45,000 (~ the poverty level for a family of four)**
- **Cumulative Risk**: Percent receiving high-intensity services:

0 risk factors: 100%

1 risk factor: ~90%

2 risk factors: ~85%

3 risk factors: ~30%

- Disparities in age at detection are reduced relative to past research; language status predicts the greatest disparity independently, but risk is cumulative.

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Issues, Challenges, and Future Directions

We are identifying children who have made contact with the services system. Massachusetts has high EI penetration but this is not true for all states.

Workforce Development & Retention: Expand training of EI providers; address barriers like EIP retention, bilingual staff recruitment, and universality of screening.

Health Systems Engineering (HSyE) methods are enabling us to visualize and model the multi-step screening process to improve efficiency and problems in implementation.

Multi-method, longitudinal, qualitative study with EIPs and parents have shed light on EI providers' opinions, preferences, and challenges with the screening process.

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Why Promote Repeat Routine Screening in Pediatric and Early Intervention Contexts?

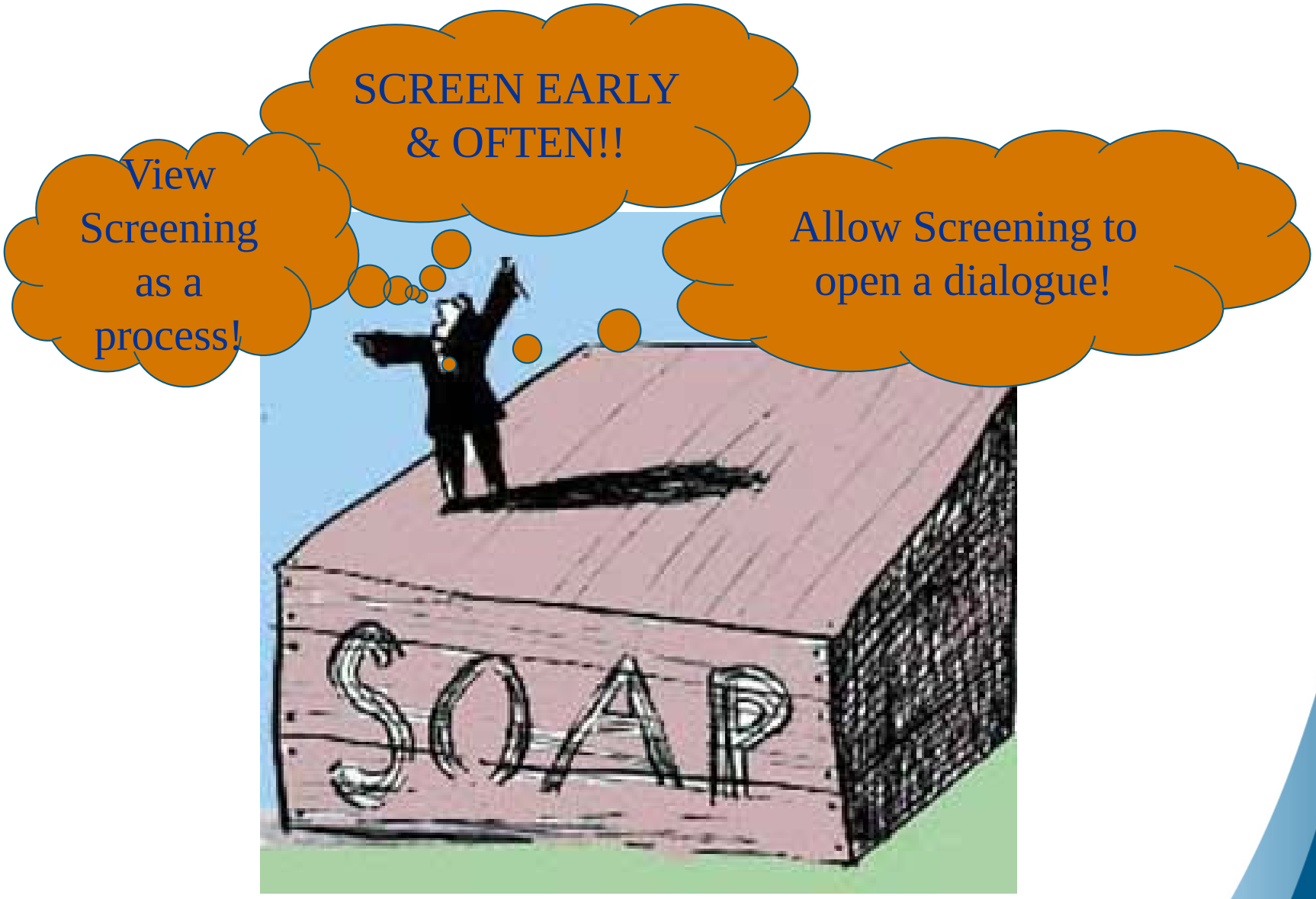
"We yearn for frictionless, technological solutions. But people talking is still the way that norms and standards change."

(Atal Gawande – New Yorker, Slow Ideas, 7/13)

In the absence of bio-markers for ASD, (as well as other developmental delays, and social-emotional and behavior problems and disorders), screening efforts must rely on parent and other caregiver reports and observations.

Open communication, supported by trusting relationships and access to care, is necessary for early detection, diagnosis, and connecting families to appropriate services.

If you take nothing else away...



LEVERAGING URBAN PRIMARY CARE SYSTEMS TO IMPROVE EARLY IDENTIFICATION OF LOW-INCOME CHILDREN WITH AUTISM SPECTRUM DISORDER

Interagency Autism Coordinating Committee
Emily Feinberg, ScD CPNP
Boston University School of Medicine
January 17, 2018

Project EARLY

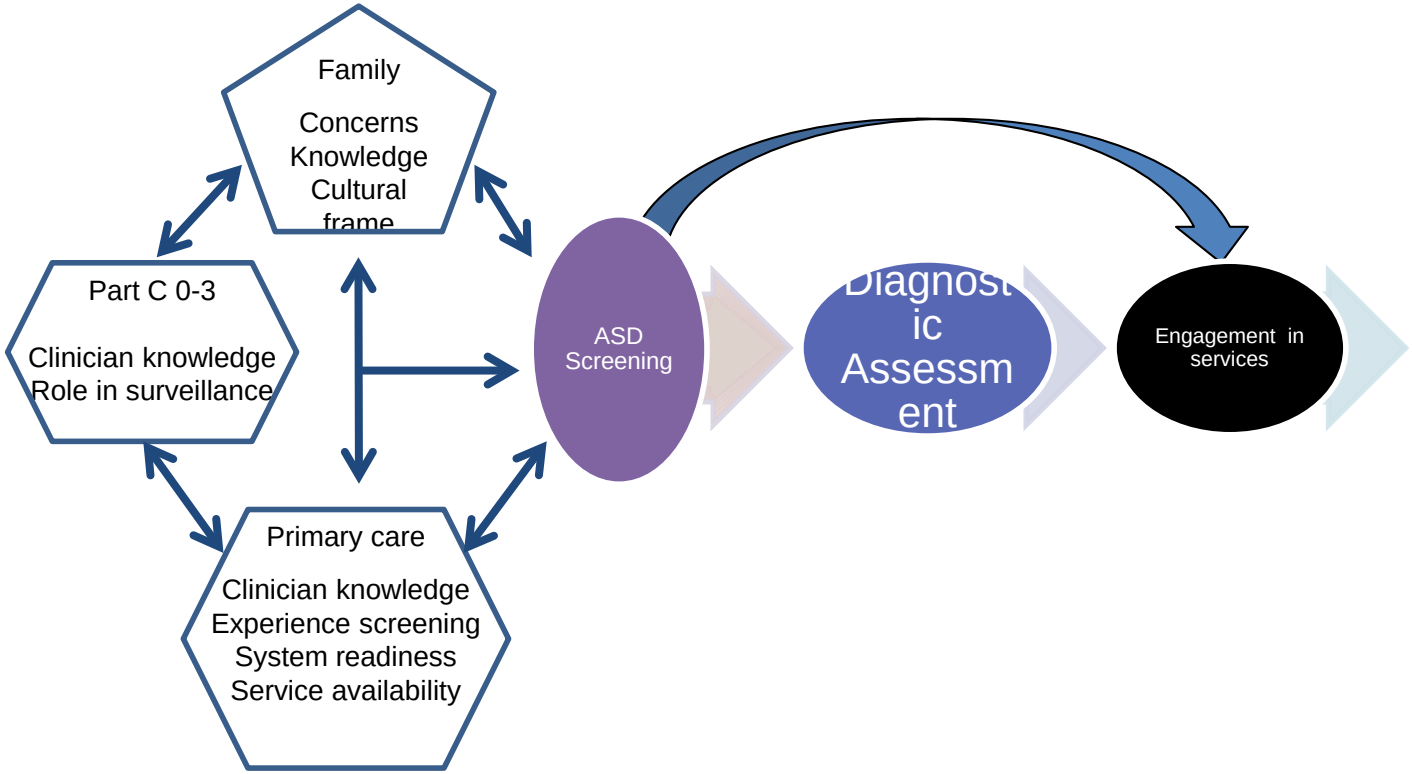
Navigating systems for young children with communication concerns

Funding Acknowledgements

- National Institute of Mental Health
  - R01MH104355 + Diversity and Disparities supplement
  - K23MH109673

- Health Service Research Administration UA3MC20218

Unpacking ASD Screening Across the ASD PEDS Network



Project EARLY: Overview

- Primary care systems-based approach
- Tailored to low-income, racial and ethnic minorities
- Grounded in Chronic Care Model
- Intergenerational focus
- Study design well aligned with USPSTF analytic framework

Building Off Previous Work

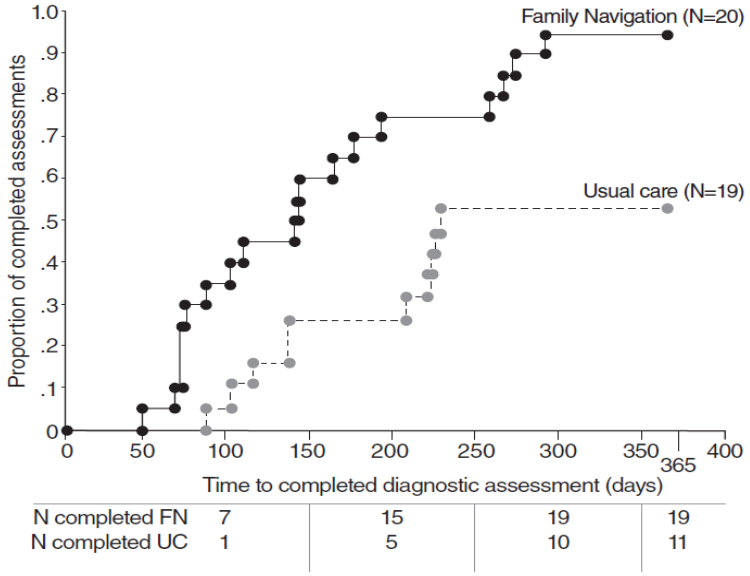
Improving Maternal Mental Health After a Child's Diagnosis of Autism Spectrum Disorder
Results From a Randomized Clinical Trial

Feinberg et al., JAMA Pediatrics, 2013

Reducing Disparities in Timely Autism Diagnosis Through Family Navigation: Results From a Randomized Pilot Trial

Feinberg et al.,Psychiatric Services, 2016

FIGURE 1. Time to completion of ASD diagnostic assessment for children who received the Family Navigation (FN) intervention or usual care (UC)[a]



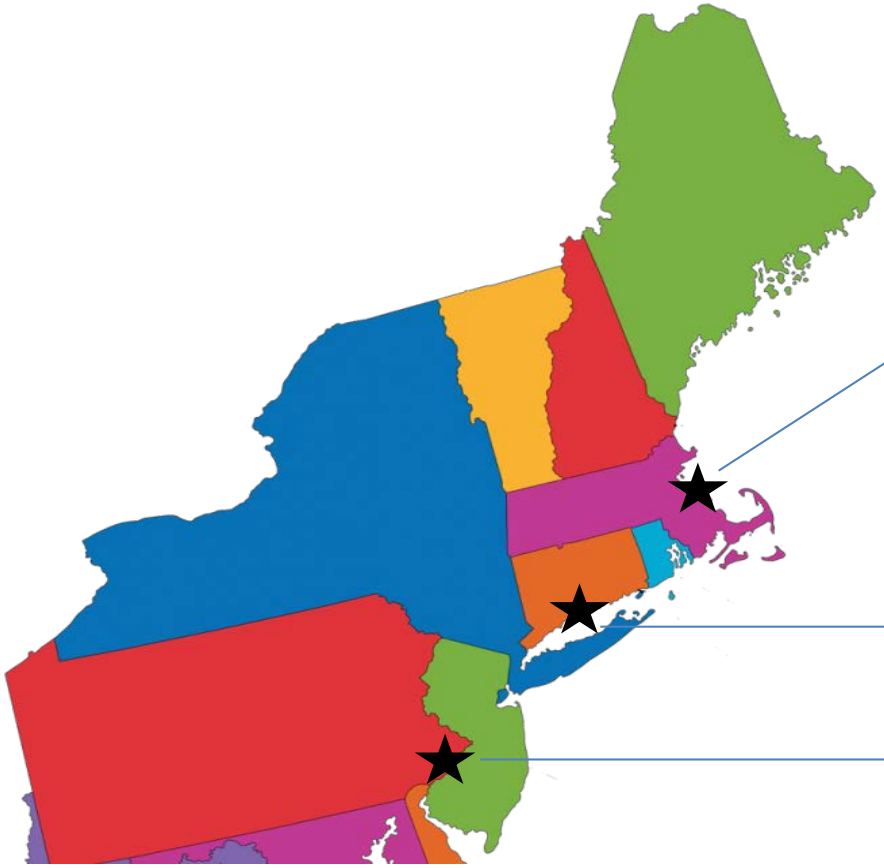
N completed FN	7	15	19	19
N completed UC	1	5	10	11

[a] ASD, autism spectrum disorder. Hazard ratio=3.21, 95% confidence interval=1.47–6.98, p<.01

Study Overview

- Hybrid comparative effectiveness trial to assess the effectiveness of a primary- care based family navigation (FN) intervention vs. traditional care management to:
  - Shorten the time to diagnosis among children suspected to have ASD;
  - Shorten the time to deployment of ASD services among those diagnosed;
  - Improve engagement with ASD services
- Concurrent implementation analysis to systematically examine key barriers and facilitators that impact FN using Consolidated Framework for Implementation Research (CFIR)
- Time series analysis to examine screening rates over time and effect of activated screening protocol

Project Early Setting



Boston Medical Center DBP clinic +
6 FQCHS
2 hospital affiliated practices

Yale University DBP clinic +
2 resident primary care clinics + 1 FQHCs

Children's Hospital of Philadelphia DBP
+
2 hospital affiliated practices

All DBP sites are members of HRSA-funded Developmental and Behavioral Pediatrics Research Network
Expected reach: 19,000 children

Study Outcomes

- Primary Outcomes
  - Diagnostic interval - number of days to diagnostic resolution
  - Time to engagement in ASD/recommended services
- Family Level Intervention Targets
  - Social support
  - Family stress
  - Parental and family functioning
- Additional Data
  - CORE ASD symptoms – ADOS
  - Child cognitive functioning – ABAS, Mullen, Vineland
  - Family use of entitlements/supports
- Serial follow-up over 12 months post enrollment

Study Population: Caregiver Characteristics

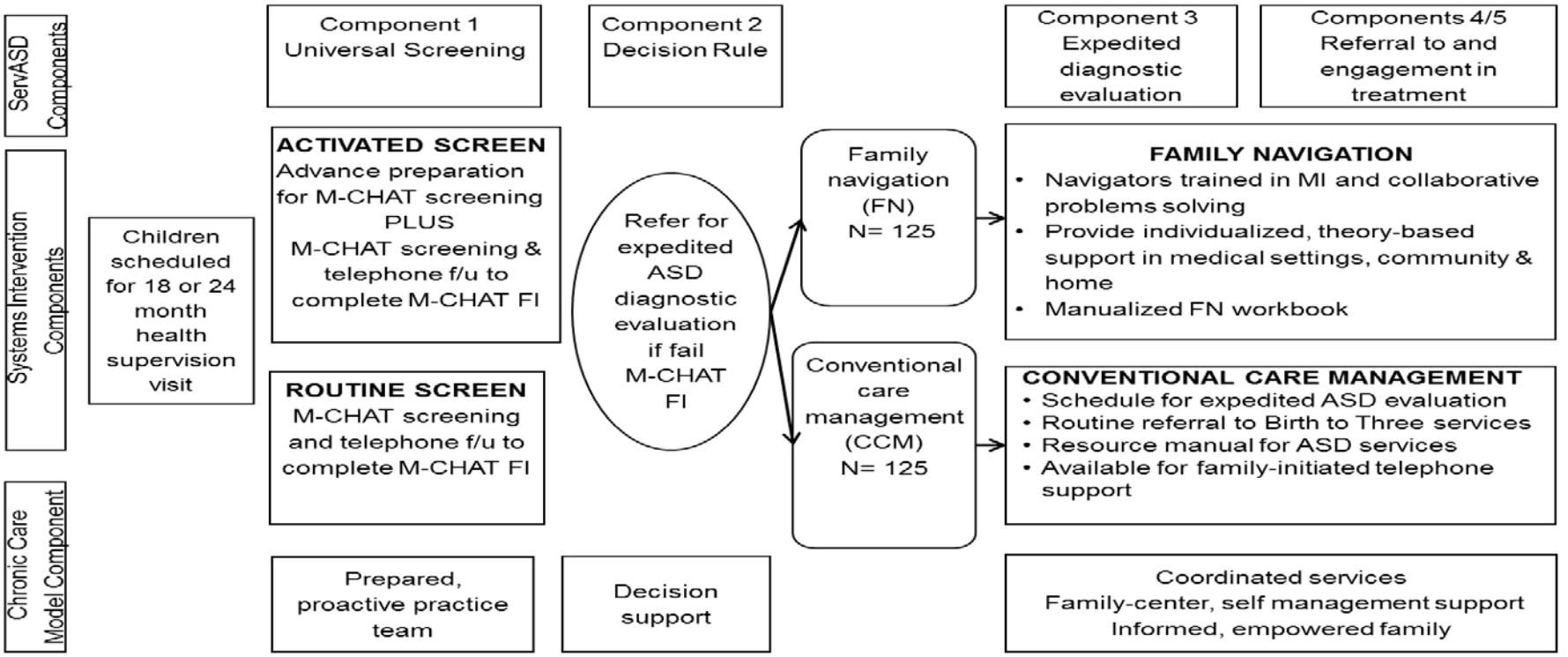
	Total (n=270)
Age, years (SD)	31.4 (7.2)
Number of children, (SD)	2.3 (1.4)
Hispanic/Latino	30%
Born outside of US	40%
Race – non-White	87%
Referral Language non-English	18%
High school graduate	80%
Married or living with a partner	54%
Currently working	54%
Public insurance	82%

Study Population: Child Characteristics

	Total (n=270)
Age, months (SD)	21.9 (3.4)
Male	70%
Modified Checklist for Autism in Toddlers MCHAT-R score (SD)	8.5 (3.1)
Receiving Early Intervention (EI) services at baseline	44%
Age started Early Intervention, months (SD)	13.18 (7.32)
Functional assessment (ABAS) Communication Scaled Score Self-Direction Scaled Score Social Scaled Score	~ 1.5 SD < norm

No statistically significant differences by arm at baseline

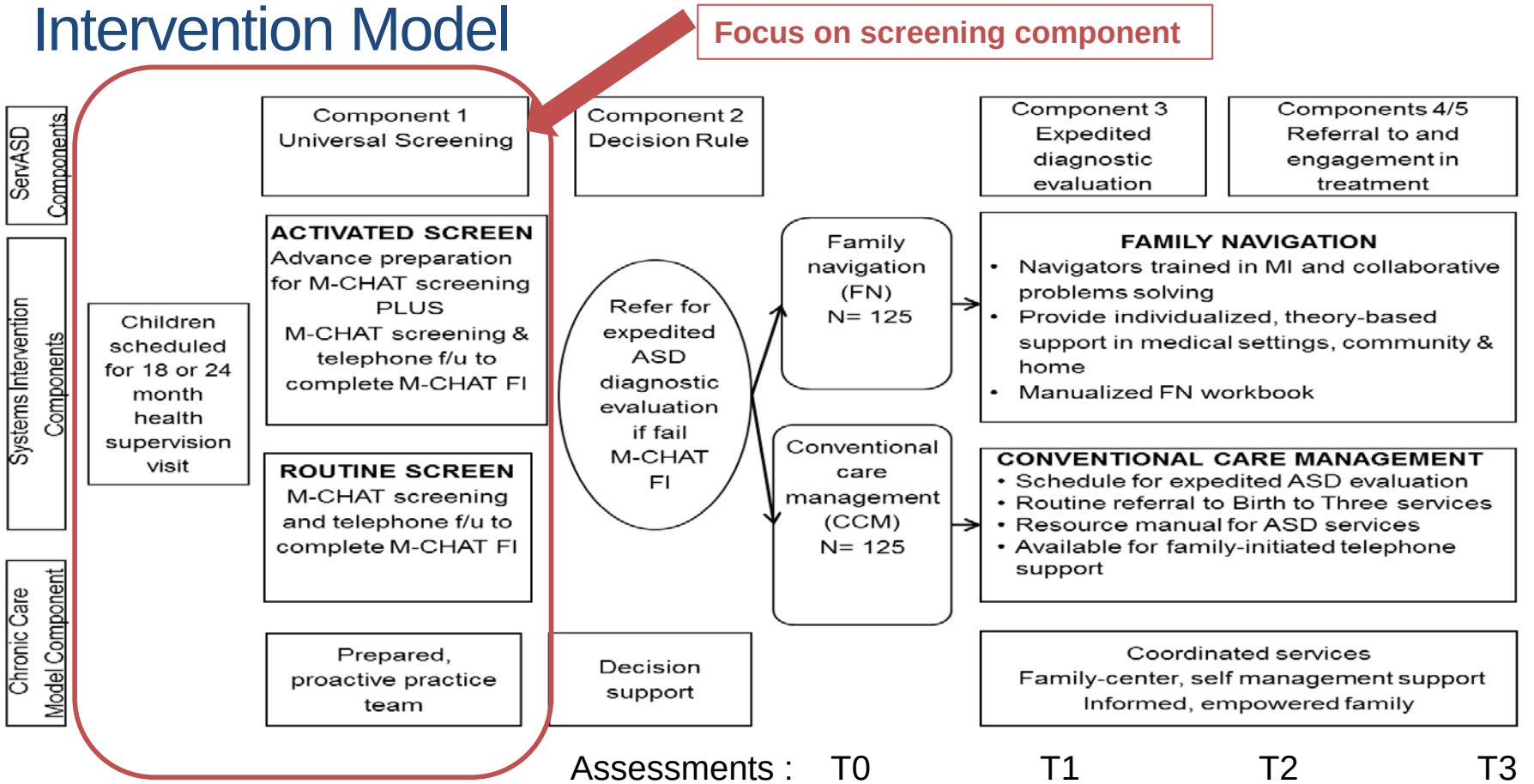
Intervention Model



Assessments : T0 Baseline T1 Post-dx T2 Post Intervention T3 12 mo

Time series analysis of screening rates

Intervention Model



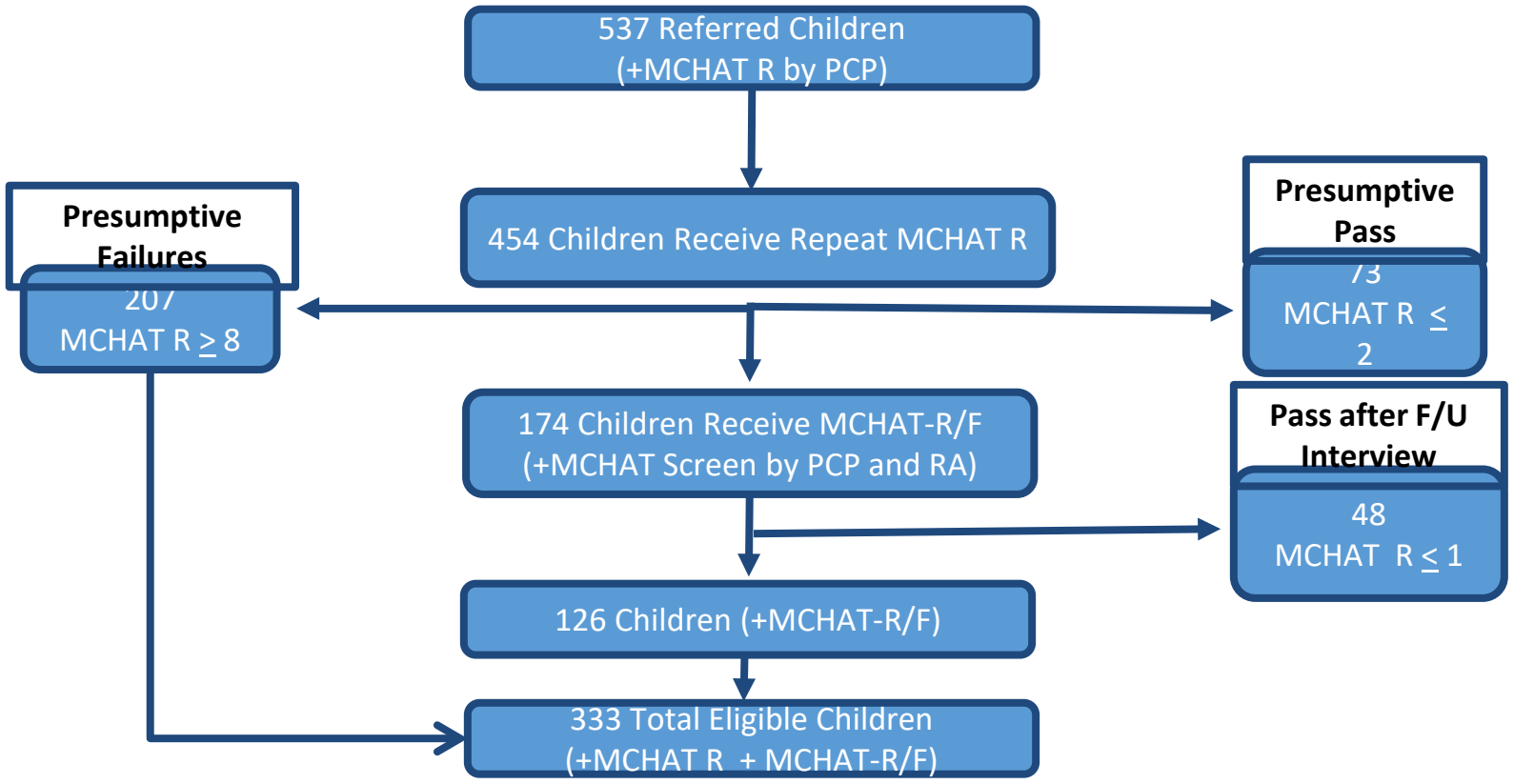
Assessments : T0 Baseline | T1 Post-dx | T2 Post Intervention | T3 12 mo

Time series analysis of screening rates

Screening Enhancements

- Centralized referral of positive screens for confirmatory screening
- MCHAT-R/F administered verbally in family's primary language
- Utilization of electronic health record to communicate results
- Loop back system to track positive PC screens that need follow-up
- Activated screening
  - Low intensity intervention to promote more activated family

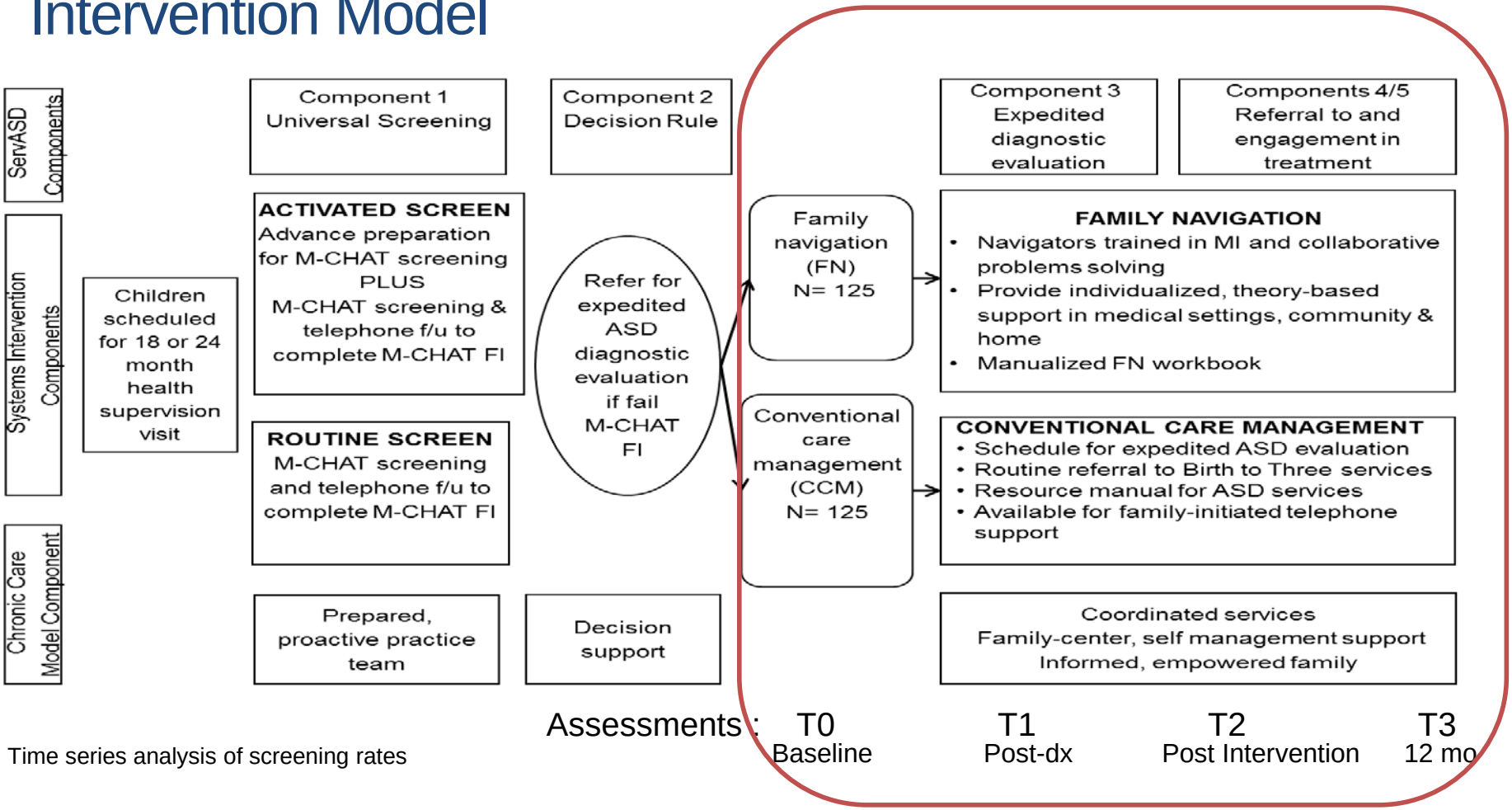
Results of Primary Care Screening and Referral



Key Learnings and New Questions

- Centralized approach to confirmatory screening acceptable and efficient
  - Number of eligible children screened: 85%
  - Time from referral to confirmatory screening: 8 days
  - Addresses literacy and linguistic barriers
  - Identified children for whom further f/u not indicated
- Confirmation of risk (positive screen) is not enough to support engagement in ASD diagnostic and treatment services for this population
- New questions and next steps
  - Why was number of children screened out so different than expected?
  - Analysis of screening data; chart review

Intervention Model



Time series analysis of screening rates

Philadelphia Navigators

Juliana Gardener, *Spanish speaker*

“I have been able to work with low income families who have been so overwhelmed by life's stressors (unemployment, housing etc.). Providing the necessary help that they need for their child that's at risk for autism, is quite rewarding. I get to partake in the joy of a parent finding out about support groups, how to apply for SSI or assisted programs, Early Headstart programs, early intervention services at no cost. Being able to provide this help for families in need is absolutely amazing!”

Juliana has worked with foster youth for over 5 years and provided ABA therapy to children in Philadelphia

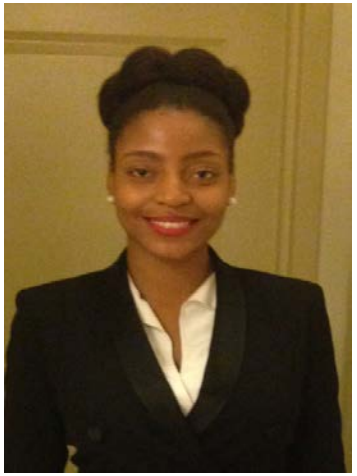
Samia Omer, *Amharic speaker*

“The most rewarding part of working as a family navigator is helping children connect with various services. The most challenge part of the work is rejection by the parents. Often, parents get overwhelmed or confused by the diagnosis and reject our offer to get the help they need for their children. Although that is very frustrating, I am always looking forward to helping families.”

Samia is originally from Ethiopia. She has a bachelor’s degree in Public Health from Temple University.

Boston Navigators

Andrea Chu, *Spanish speaker*
“As a navigator, I have worked closely with families to arrange transportation to appointments, inform them of available services, and to complete necessary paperwork. Above all, I provide emotional support for families during this overwhelming time. Families often need time to process the diagnosis and decide next steps, as they sometimes are also faced with family members’ denial towards the autism diagnosis. The relationships we build with families are very important as the navigator may be one of the few sources of support and information for families.”



Mitsouka Exantus, *Haitian-Creole Speaker*
"When we first meet families, they are often experiencing a range of emotions: confusion, anxiety, resistance, and ambivalence. It is a privilege to build a relationship where a family is comfortable sharing private worries and concerns that they may not be able to voice to other family members, friends, or even their health care providers. This allows us to take a deeper look into our families' needs, and support them to our best ability--it is incredible how much can change in a couple of months. By the end of navigation, we often see our families becoming more engaged and empowered in their child's healthcare."

New Haven Navigator

Jenny Acevedo

Born in Colombia, Spanish speaker

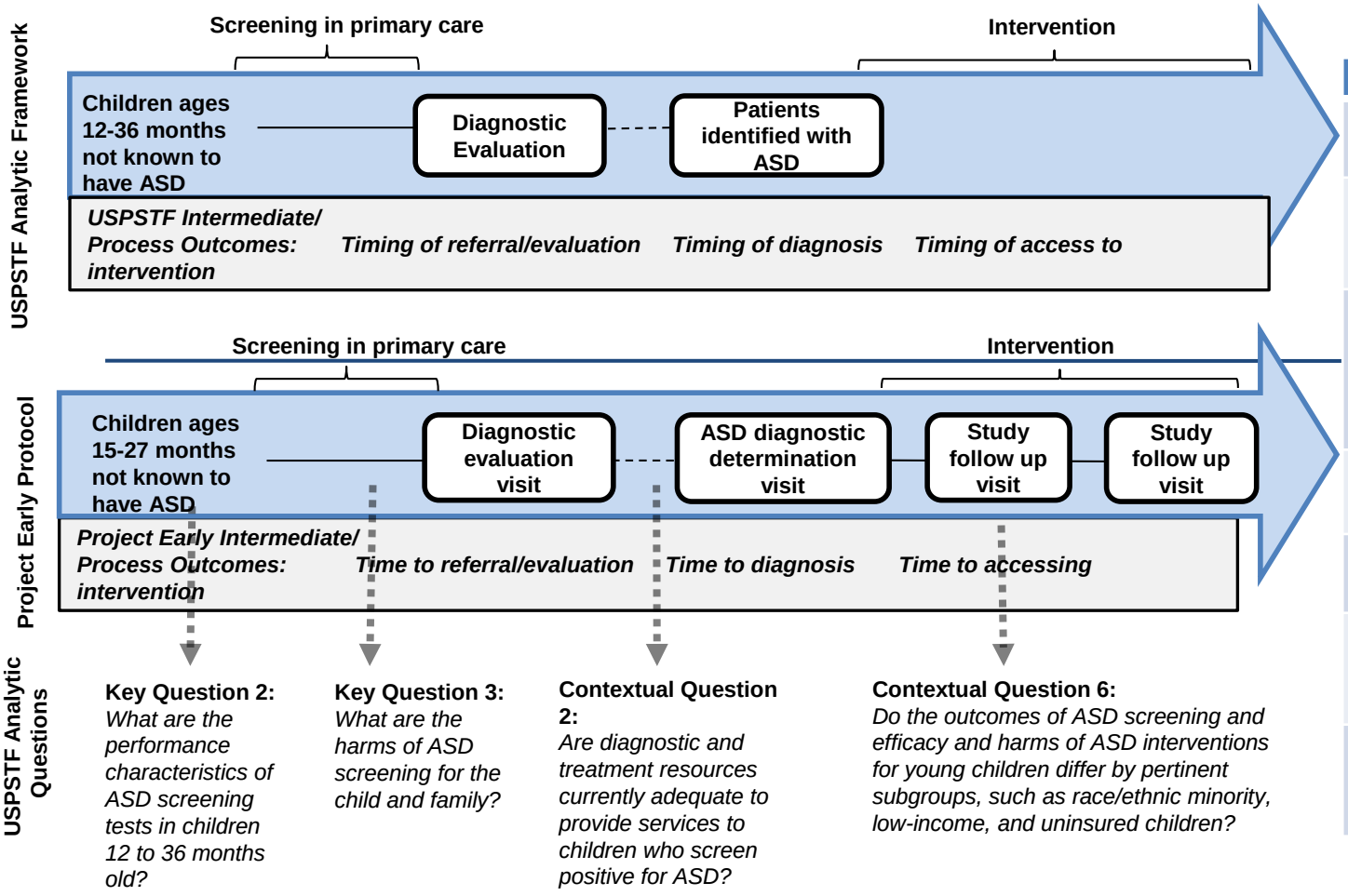
“What I find most rewarding about being a Family Navigator is being able to provide support to parents during a very challenging time in their life. I worked with a family who was facing homelessness during the Thanksgiving Holiday. I assisted the young mother in finding shelter, by making phone calls and advising her on what to say to be considered priority. She was placed in a shelter for about 2 months and thankfully connected to a program where they helped her find an apartment of her own. Mom also did not have a reliable babysitter and missed many days from work. I provided mom with names of different daycares and shortly after she registered her child at a daycare center. A referral was made and the child started Early Intervention services where he received many therapies. At the 3 month follow up appointment the Mother reported significant progress in her child. Cases like this make being a Family Navigator extremely rewarding.”

Navigation Measures

- Navigation process measures
  - Number of contacts
  - Type and location of contacts
  - Time:
  - Issues addressed
  - Fidelity: Visit content and use of MI

Figure 1. Overlap Between USPSTF Analytic Framework and Project Early

Key Question 1: *Is Screening for ASD Conducted in Children 12 to 36 Months Old Associated with Improved Short- and Long-Term Outcomes?*



USPSTF Health-related Outcomes and Correlated Project Early Measures

USPSTF	Project Early
Core ASD symptoms	ADOS
Cognitive/ intellectual functioning	ADOS, Mullen
Language & communication skill development	ADOS, ABAS, Vineland, Mullen
Challenging behavior	Vineland, APSI
Adaptive behavior	ABAS, Vineland
Educational placement/ achievement	School record review
Quality of life	APSI, PSI, PSS MOSS, FIQ, VR12,

Acknowledgements

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Amanda Bennett
Nate Blum
Manju Abraham
Juliana Gardener
Jim Guevara
Samia Omer

Committee Discussion

Afternoon Break

Meeting of the IACC

Afternoon Agenda - continued

4:00	**Afternoon Break**
4:15	**Round Robin**
5:00	**Closing Remarks and Adjournment**

Round Robin

Closing Remarks
Adjournment

Upcoming IACC Meeting

Next IACC Meeting:

Thursday, April 19, 2018