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

Interagency Autism Coordinating Committee

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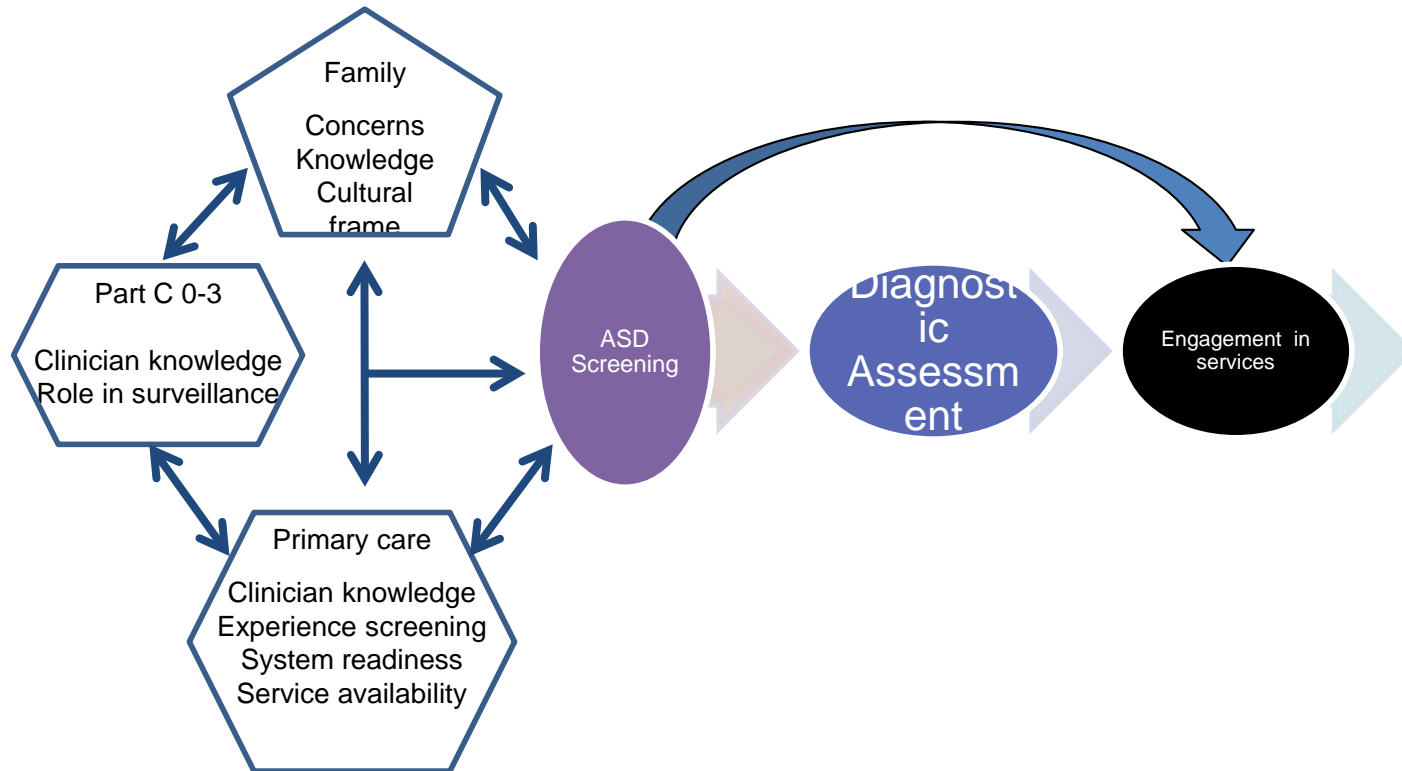Boston University School of Medicine

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Project EARLY

Navigating systems for young children with communication concerns

Funding Acknowledgements

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]
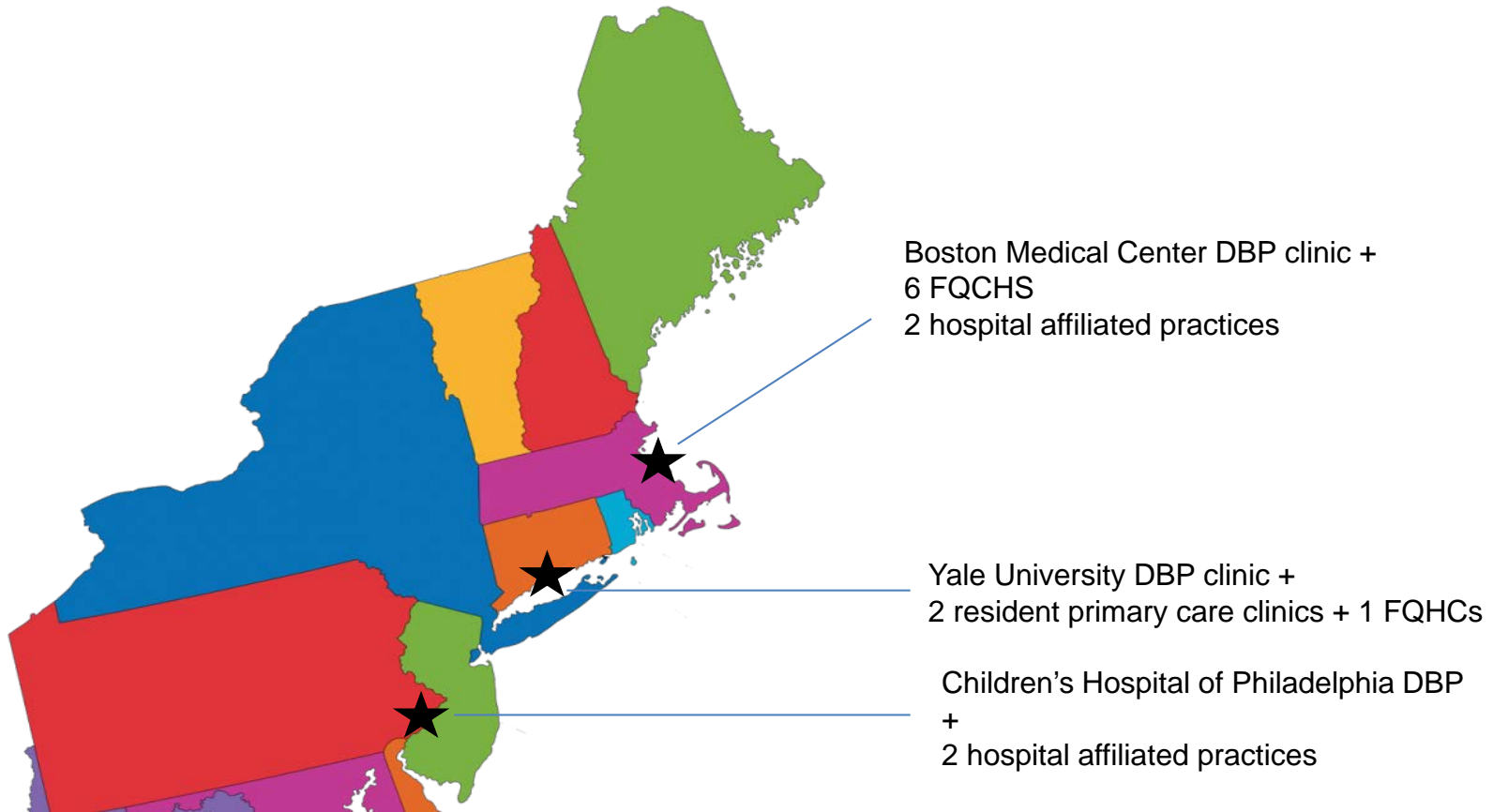

| N completed FN | 7 | 15 | 19 | 19 |
| N completed UC | 1 | 5 | 10 | 11 |
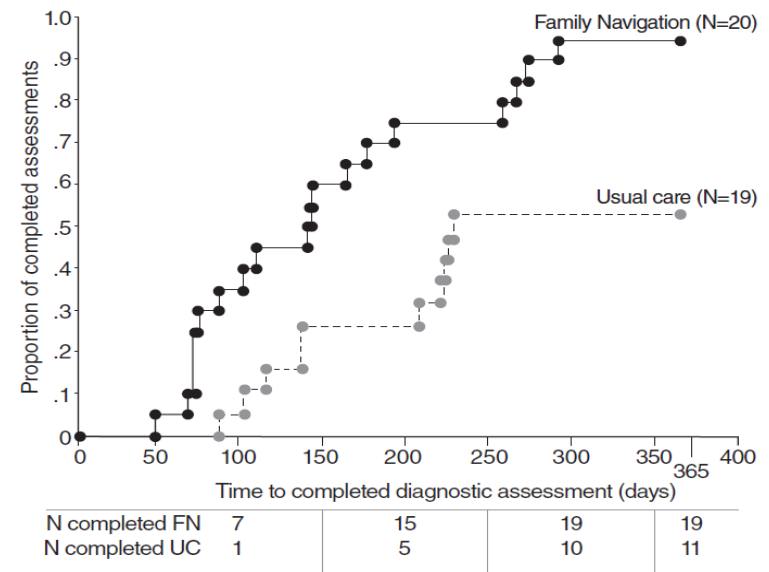
[a] ASD, autism spectrum disorder. Hazard ratio=3.21, 95% confidence interval=1.47−6.98, p<.01

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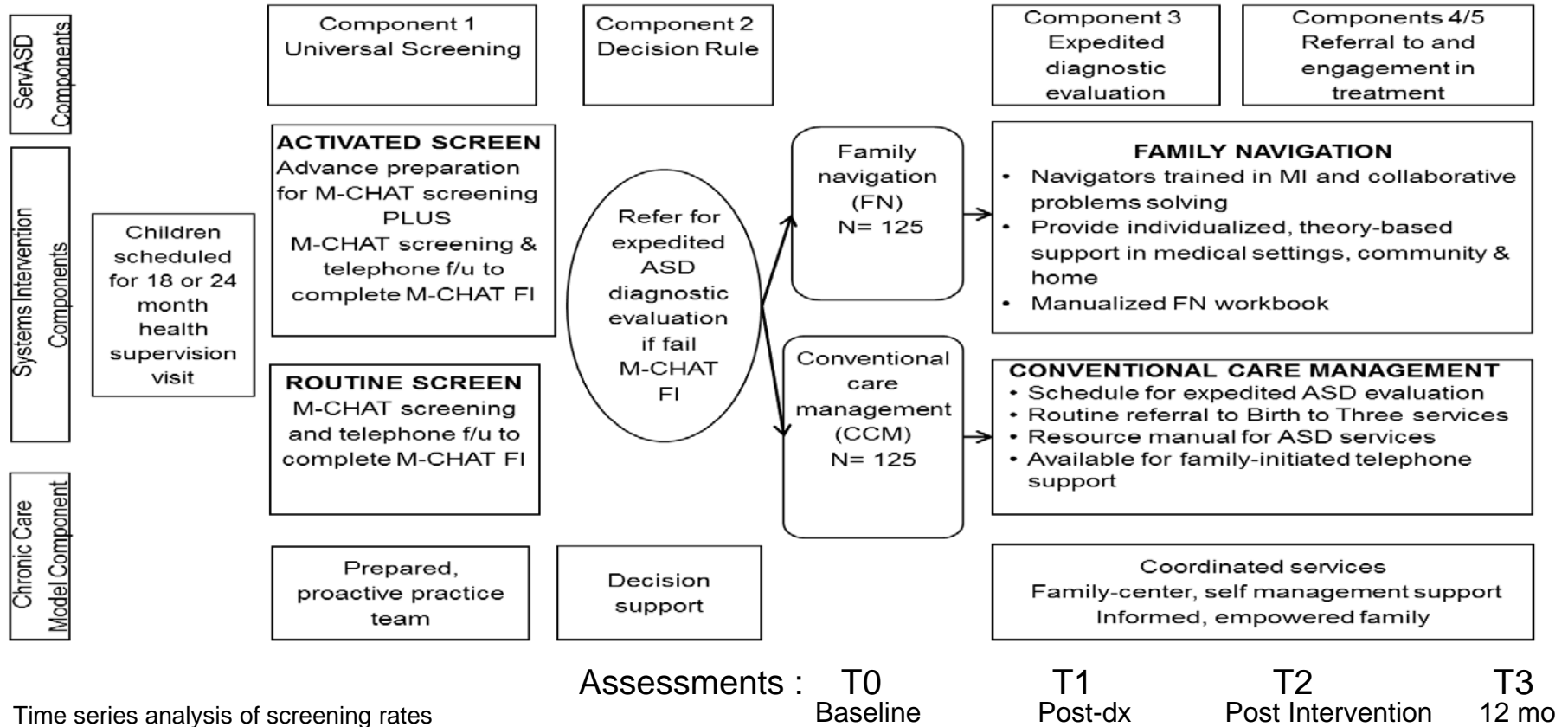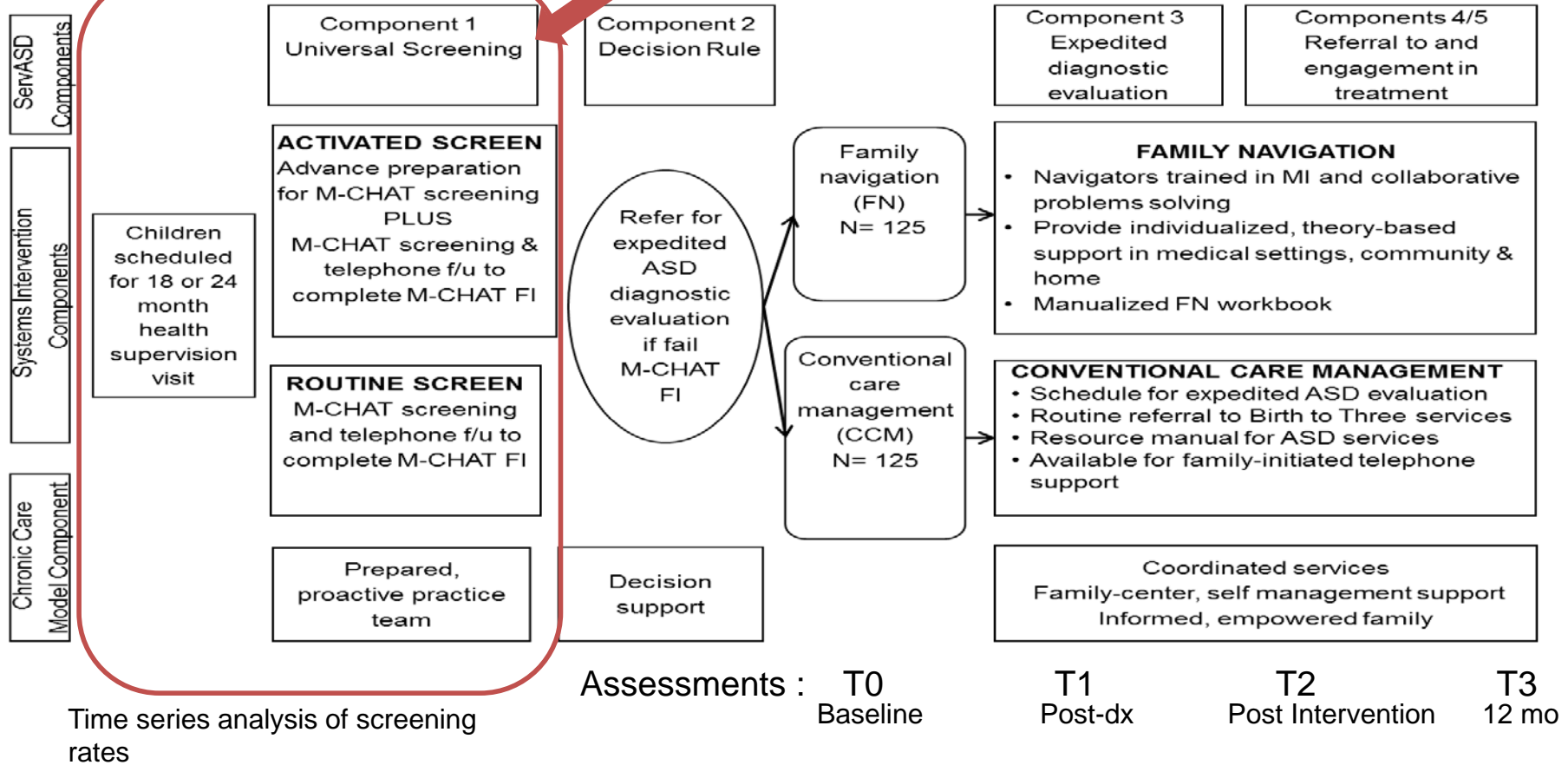
Assessments :   T0   T1   T2   T3
                Baseline   Post-dx   Post Intervention   12 mo

Time series analysis of screening rates

Intervention Model

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
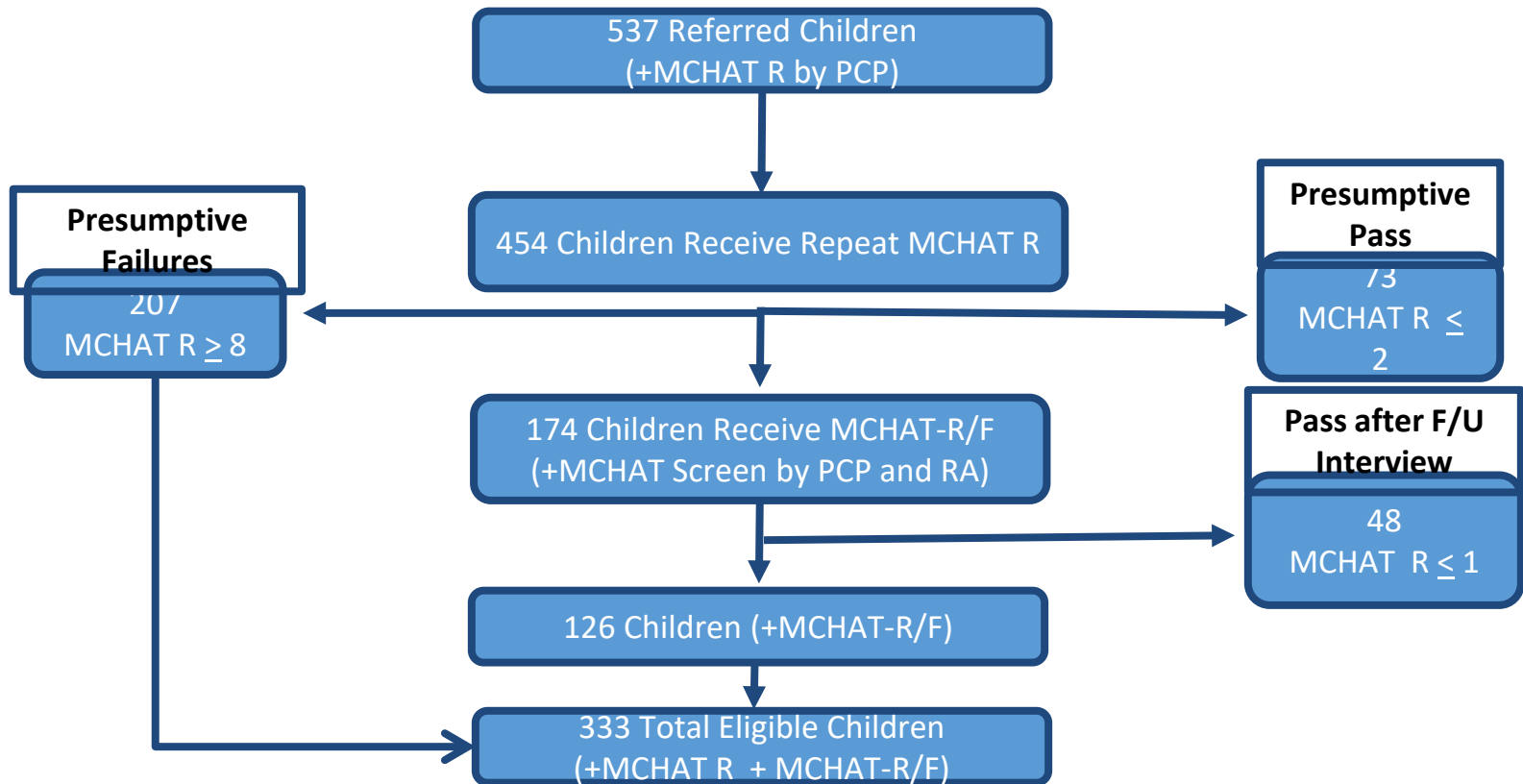
Key Learnings and New Questions

- 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

ServASD Components	Component 1 Universal Screening	Component 2 Decision Rule		Component 3 Expedited diagnostic evaluation	Components 4/5 Referral to and engagement in treatment

ACTIVATED SCREEN
Advance preparation for M-CHAT screening PLUS
M-CHAT screening & telephone f/u to complete M-CHAT FI

Children scheduled for 18 or 24 month health supervision visit

ROUTINE SCREEN
M-CHAT screening and telephone f/u to complete M-CHAT FI

Refer for expedited ASD diagnostic evaluation if fail M-CHAT FI

Family navigation (FN) N= 125

FAMILY NAVIGATION
- Navigators trained in MI and collaborative problems solving
- Provide individualized, theory-based support in medical settings, community & home
- Manualized FN workbook

Conventional care management (CCM) N= 125

CONVENTIONAL CARE MANAGEMENT
- Schedule for expedited ASD evaluation
- Routine referral to Birth to Three services
- Resource manual for ASD services
- Available for family-initiated telephone support

Prepared, proactive practice team

Decision support

Coordinated services
Family-center, self management support
Informed, empowered family

Systems Intervention Components

Chronic Care Model Component

Assessments: T0   T1   T2   T3
Time series analysis of screening rates   Baseline   Post-dx   Post Intervention   12 mo

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."
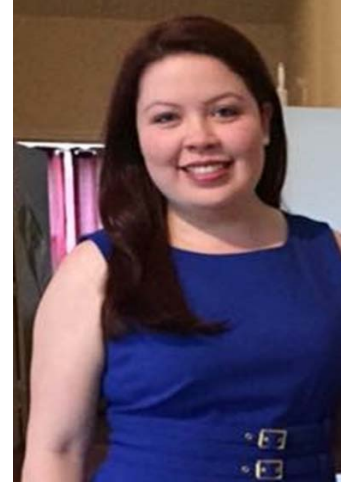
Mitsouka Exantus, *Haitian-Creole Speaker*
"When we first meet families, they are often experiencing a range of emotions: confusion, anxiety, resistance, and ambivalence. It is a privilege to build a relationship where a family is comfortable sharing private worries and concerns that they may not be 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."
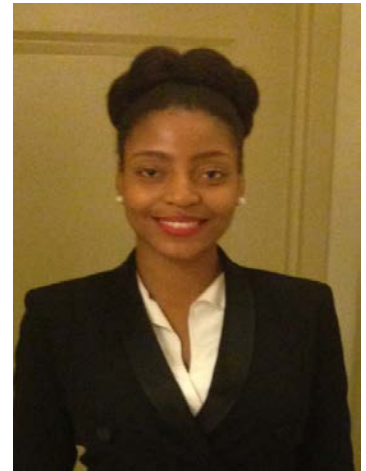
New Haven Navigator

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."
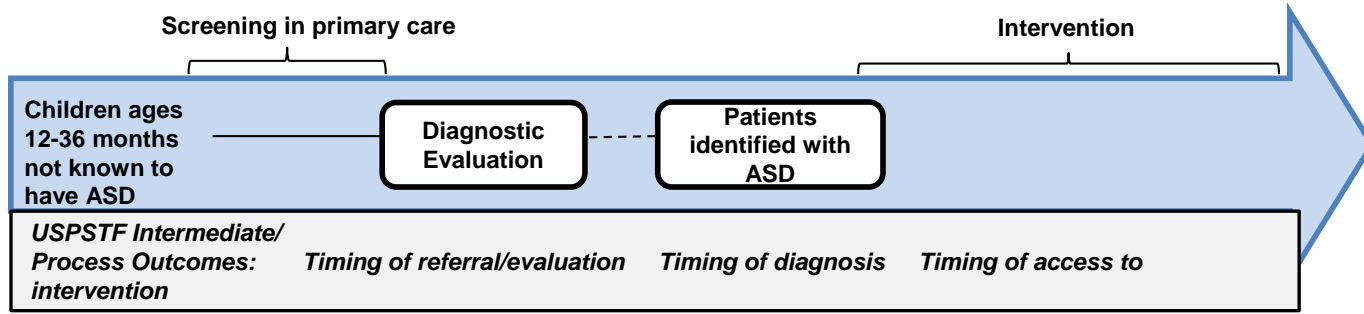
Navigation Measures

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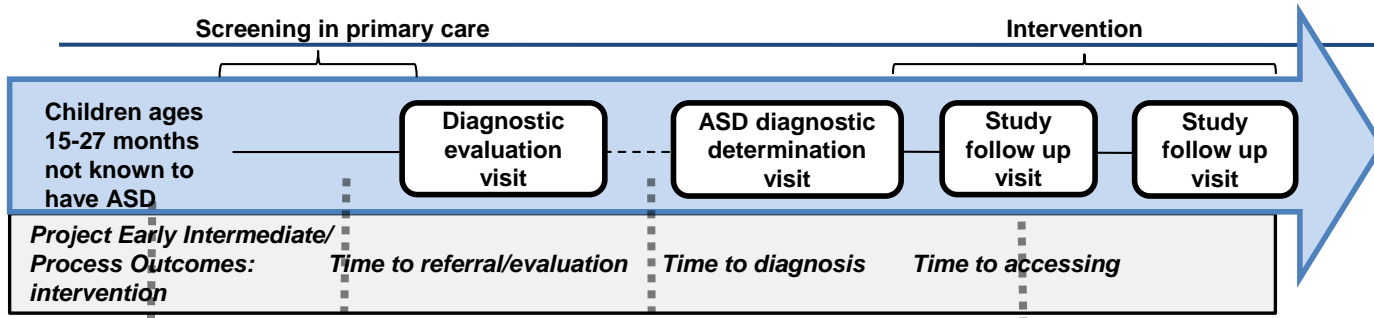 - Fidelity: Visit content and use of MI

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 Analytic Framework

Screening in primary care | Intervention

Children ages 12-36 months not known to have ASD → **Diagnostic Evaluation** ----> **Patients identified with ASD**

USPSTF Intermediate/ Process Outcomes: intervention   *Timing of referral/evaluation*   *Timing of diagnosis*   *Timing of access to*

Project Early Protocol

Screening in primary care | Intervention

Children ages 15-27 months not known to have ASD → **Diagnostic evaluation visit** ----> **ASD diagnostic determination visit** — **Study follow up visit** — **Study follow up visit**

Project Early Intermediate/ Process Outcomes: intervention   *Time to referral/evaluation*   *Time to diagnosis*   *Time to accessing*

USPSTF Analytic Questions

Key Question 2: *What are the performance characteristics of ASD screening tests in children 12 to 36 months old?*

Key Question 3: *What are the harms of ASD screening for the child and family?*

Contextual Question 2: *Are diagnostic and treatment resources currently adequate to provide services to children who screen positive for ASD?*

Contextual Question 6: *Do the outcomes of ASD screening and efficacy and harms of ASD interventions for young children differ by pertinent subgroups, such as race/ethnic minority, low-income, and uninsured children?*

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,

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