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

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IACC Presentation

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Collaborators: Work that Takes a Village

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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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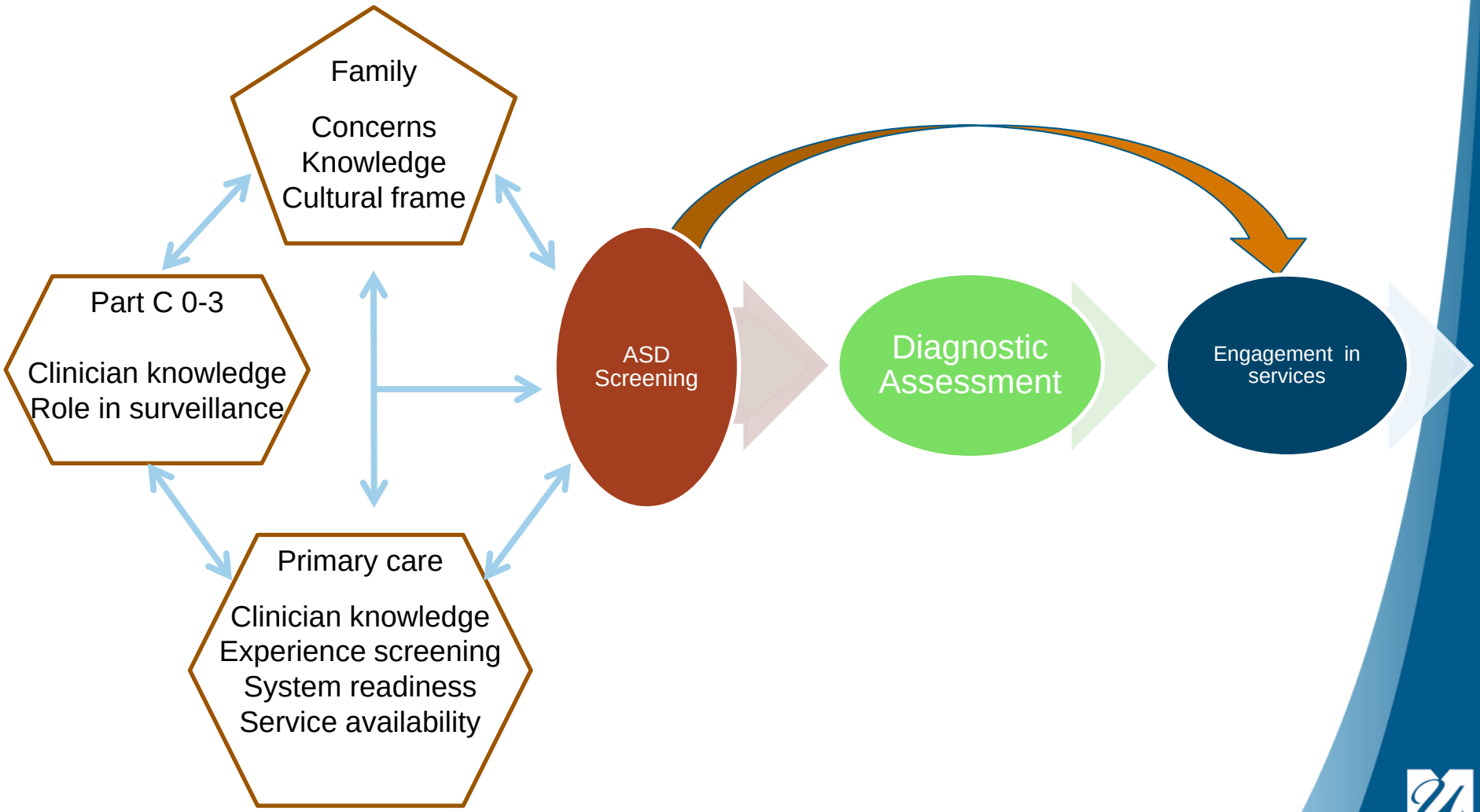
Unpacking ASD Screening Across the ASD PEDS Network



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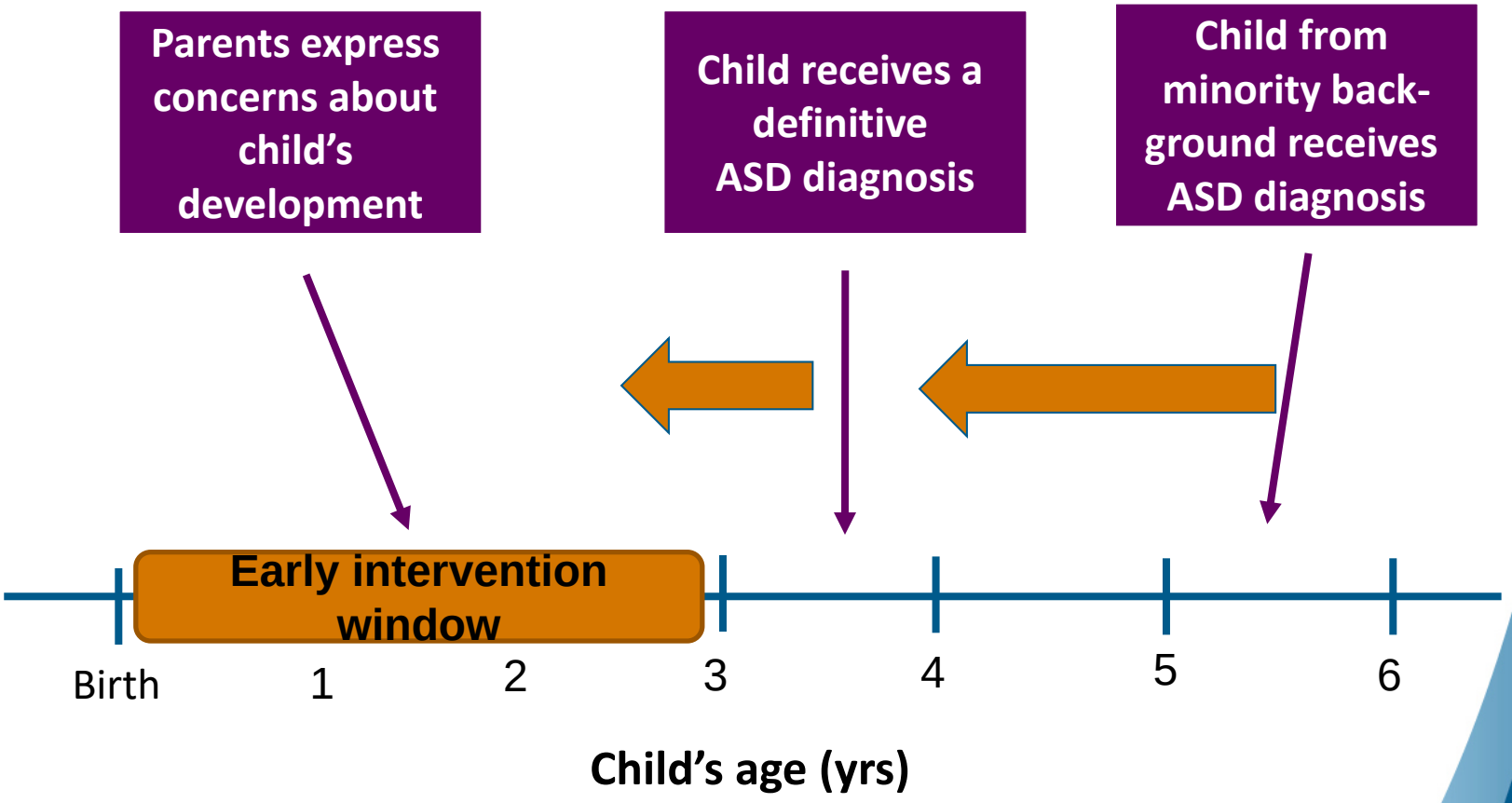
The diagnostic timeline

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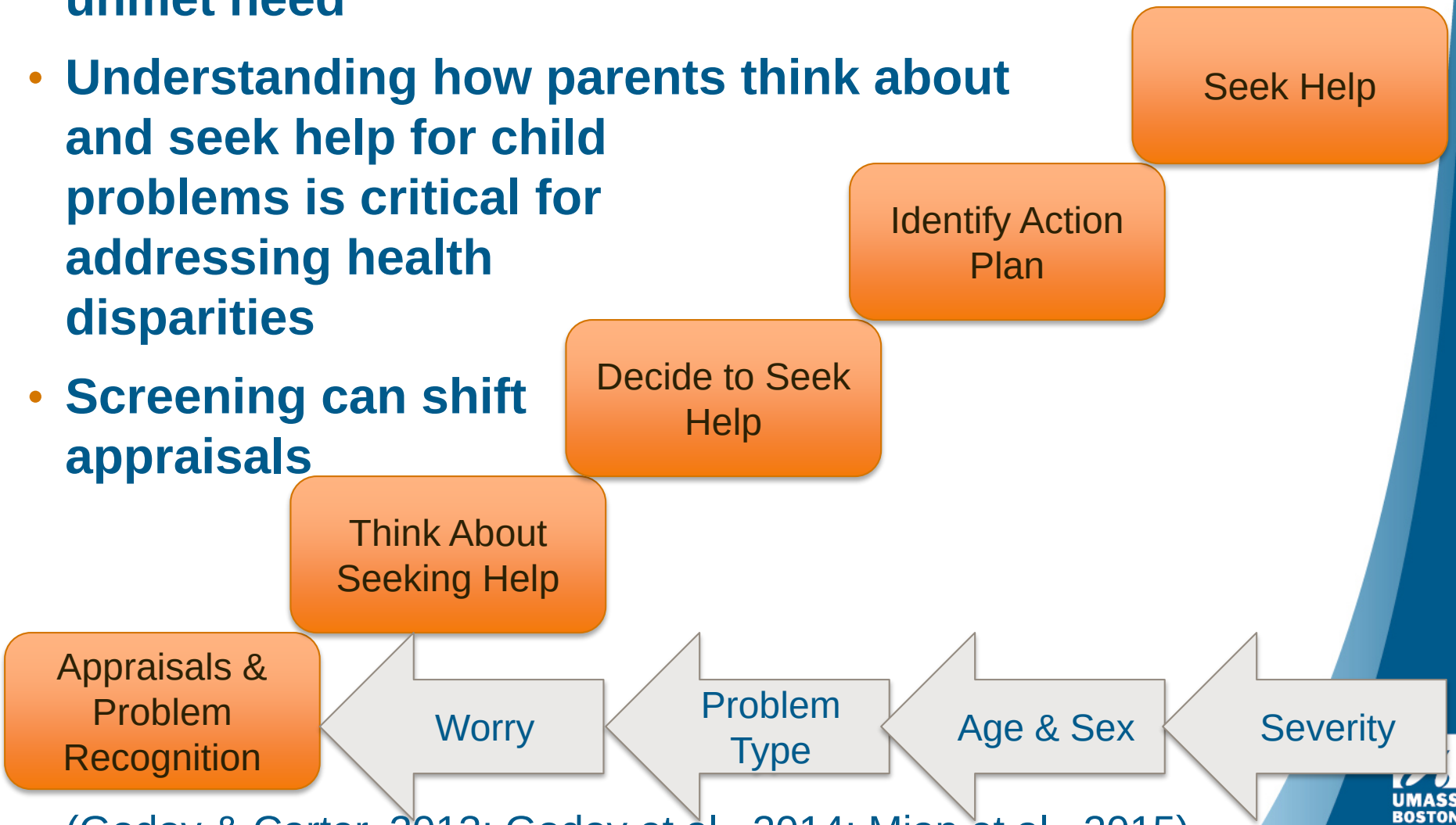
Parent Appraisals & Help Seeking Models: Applied to the Screening Context

- **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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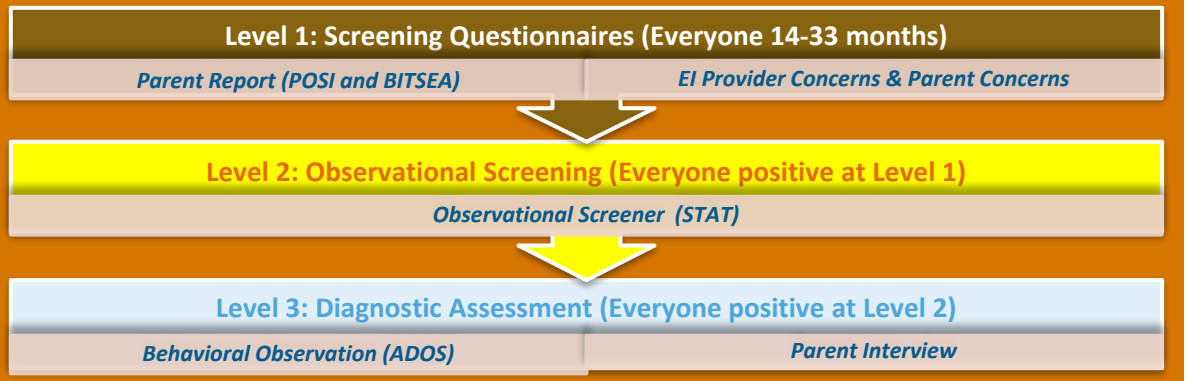
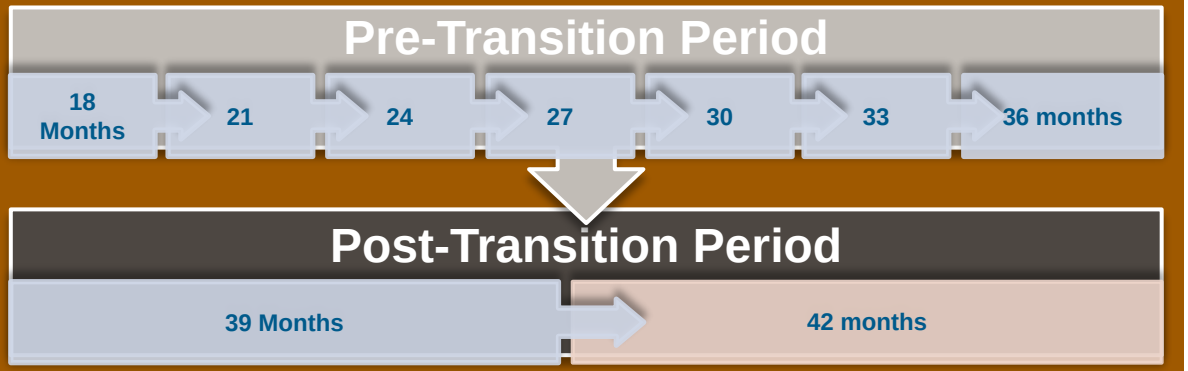
Phase I

Screening & Assessment Protocol



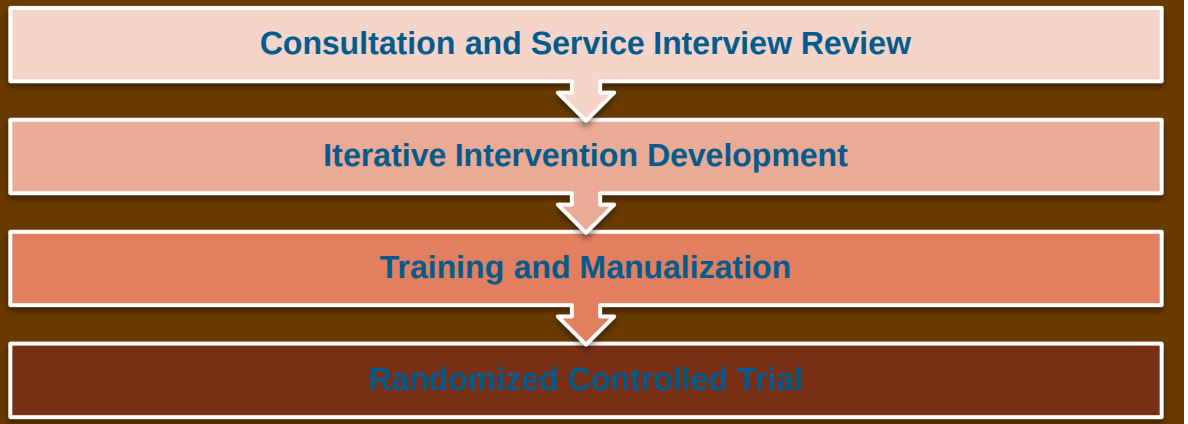
Phase II

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

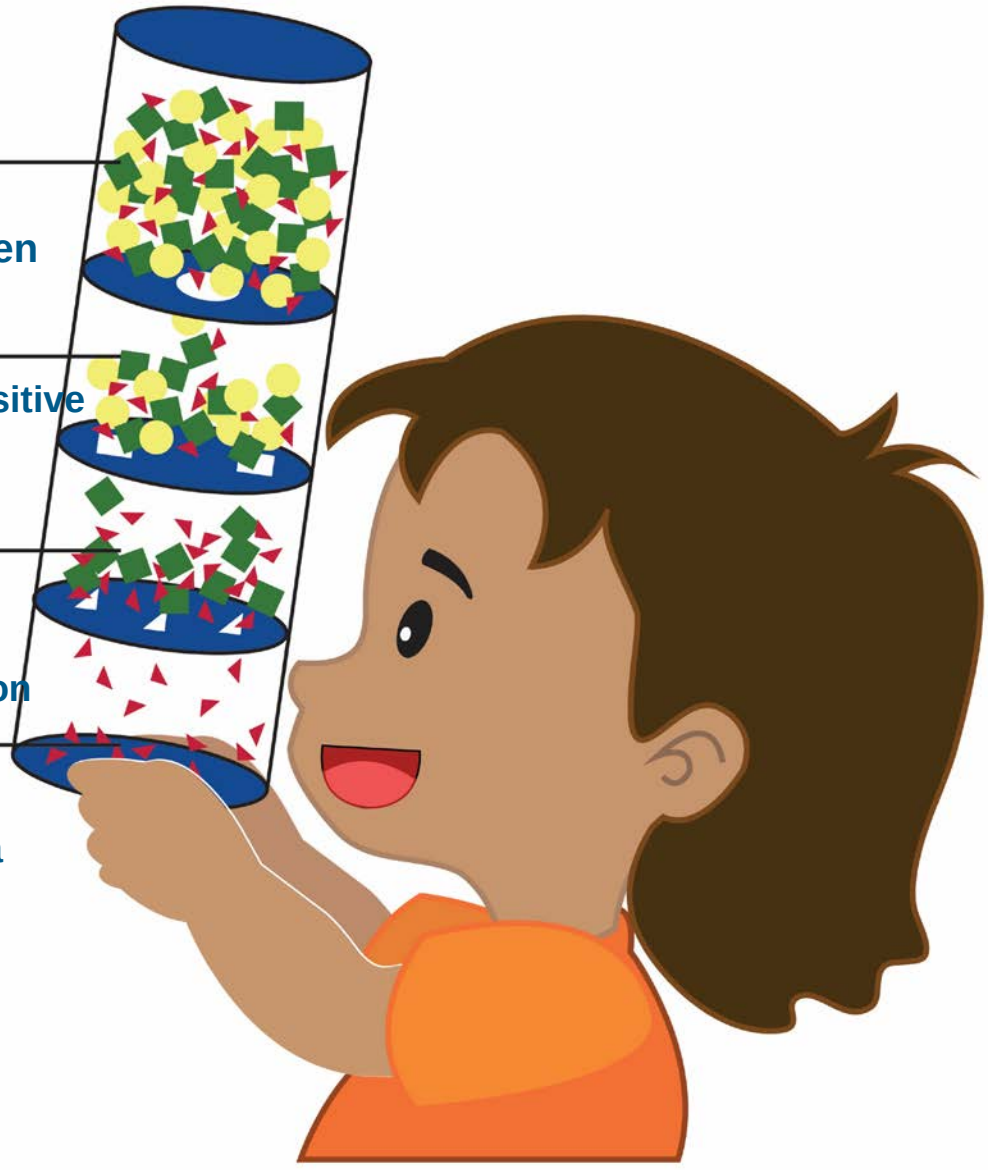
STAGE 2

~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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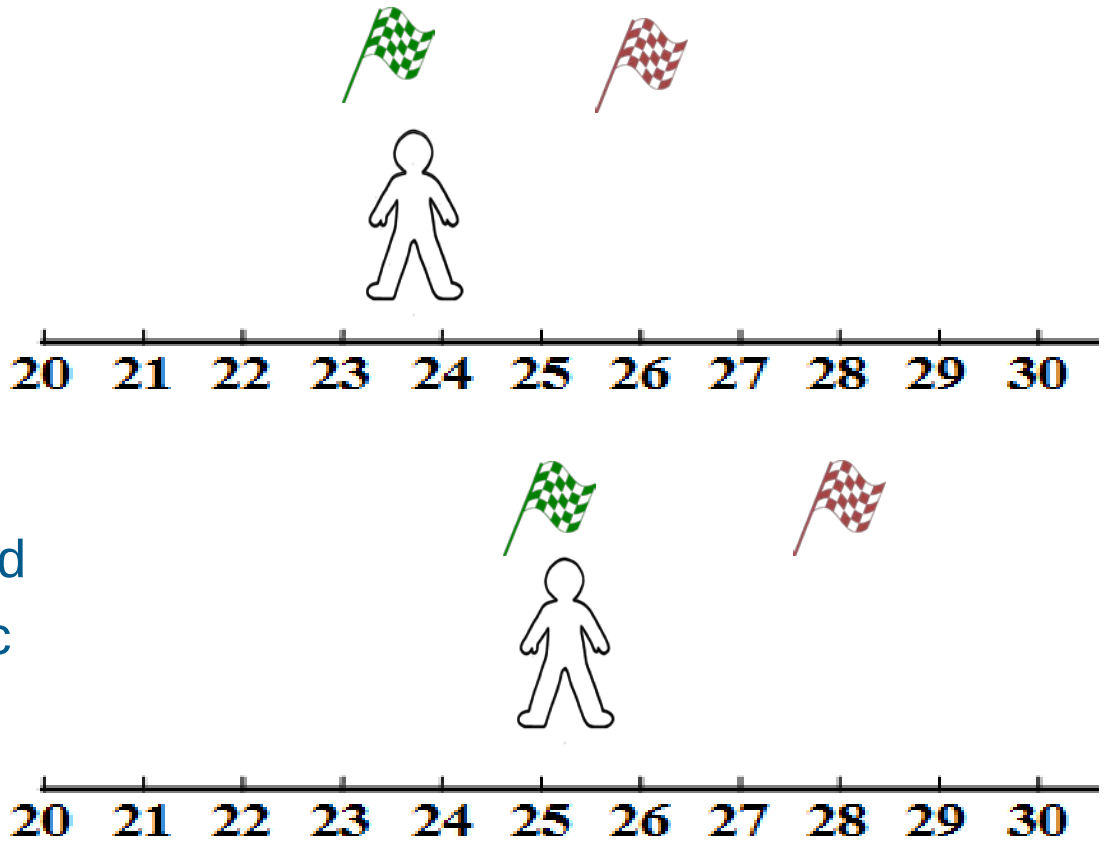
Is Race a Factor in Screening Process Timing?

White,
Non-Hispanic

Non-White, and
White Hispanic



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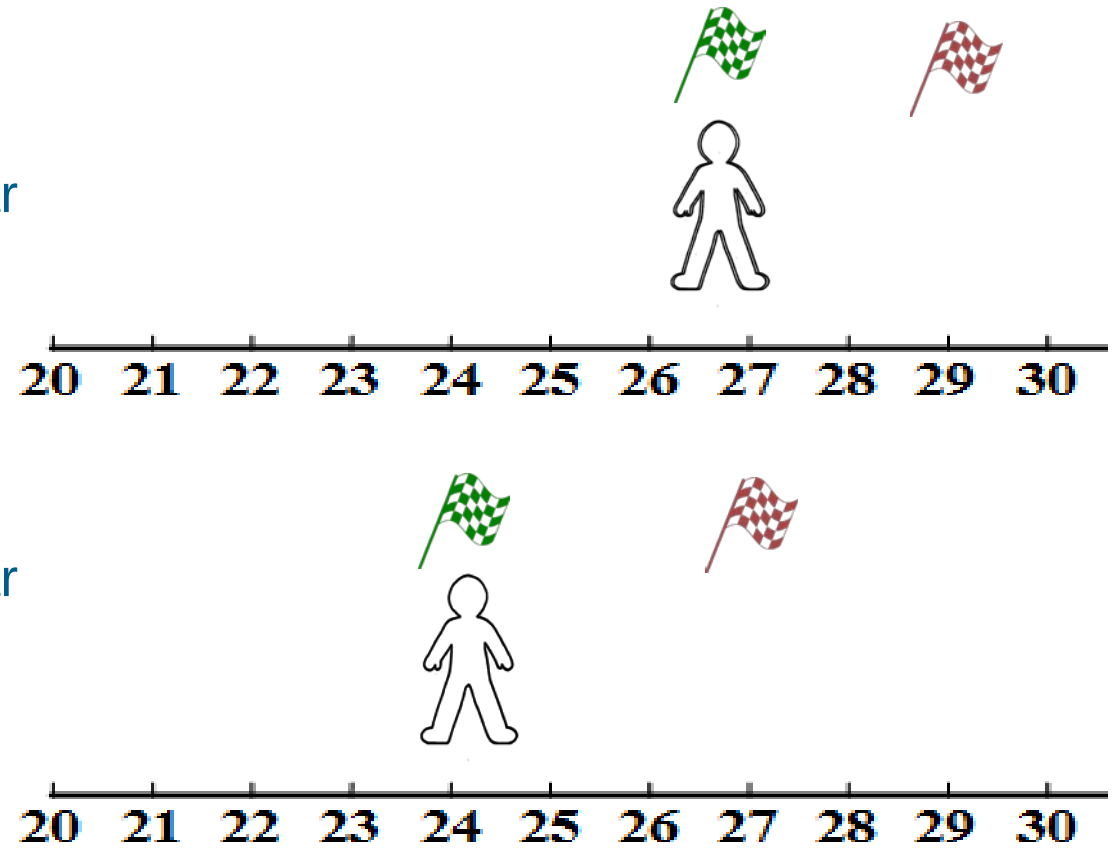
Is Income a Factor in Screening Process Timing?

> $45,000/year

< $45,000/year



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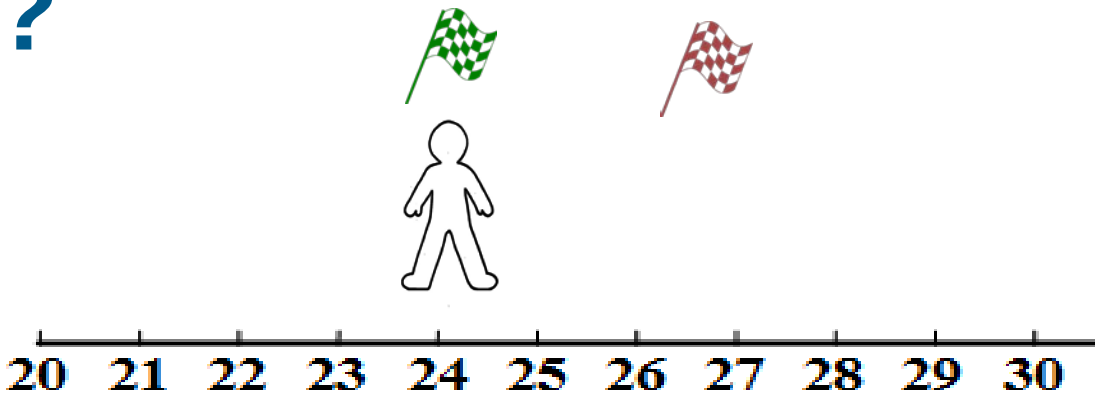
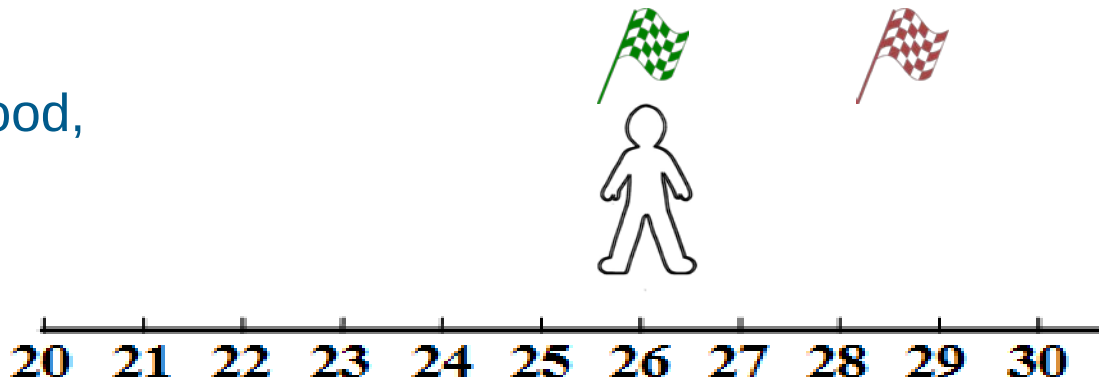
Is English Language Proficiency a Factor in Screening Process Timing?

Excellent



Very Good, Good, Fair or Poor



Months

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Phase I

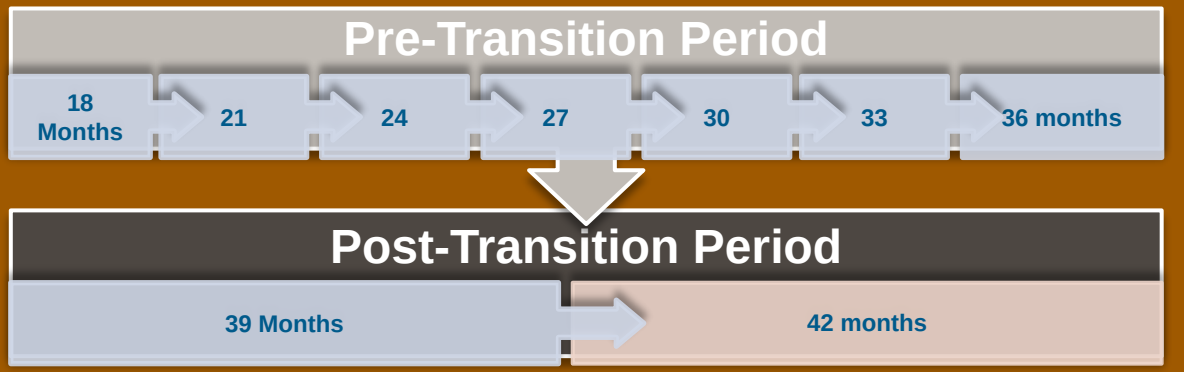
Screening

& 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...