

Integrating Ohio Early Hearing Detection and Intervention (EHDI) with state-level data systems to assess longitudinal outcomes for children who are deaf/hard of hearing

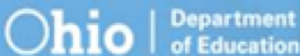
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Department of
Developmental Disabilities



Funding Support



- CDC-funded Disability Research and Dissemination Center grant U01DD001007

Objective of current study

- **Assess developmental outcomes of children who are deaf/hard of hearing (D/HH) identified through the Ohio EHDI program**
 - **Focus on language and early literacy**
- *Created a comprehensive longitudinal database of children born in the state of Ohio with permanent hearing loss by data across 3 state agencies*

OHIO

County Map



Agencies Involved and Data System

Ohio State Agencies

Department of Health (ODH)

Department of Developmental Disabilities (DODD)

Demographics, percent of time educated, attendance and absence days, disability condition, grade level, early childhood assessments, individualized education plans (IEP), educational labels, standardized assessments

Infant: Dates (screening, diagnosis) information regarding hearing loss (severity, laterality), risk factors, birth weight, GA, apgar, primary communication options, race, risk indicators
Caregiver: education (mom and dad), insurance, race

LINKS with birth certificate)

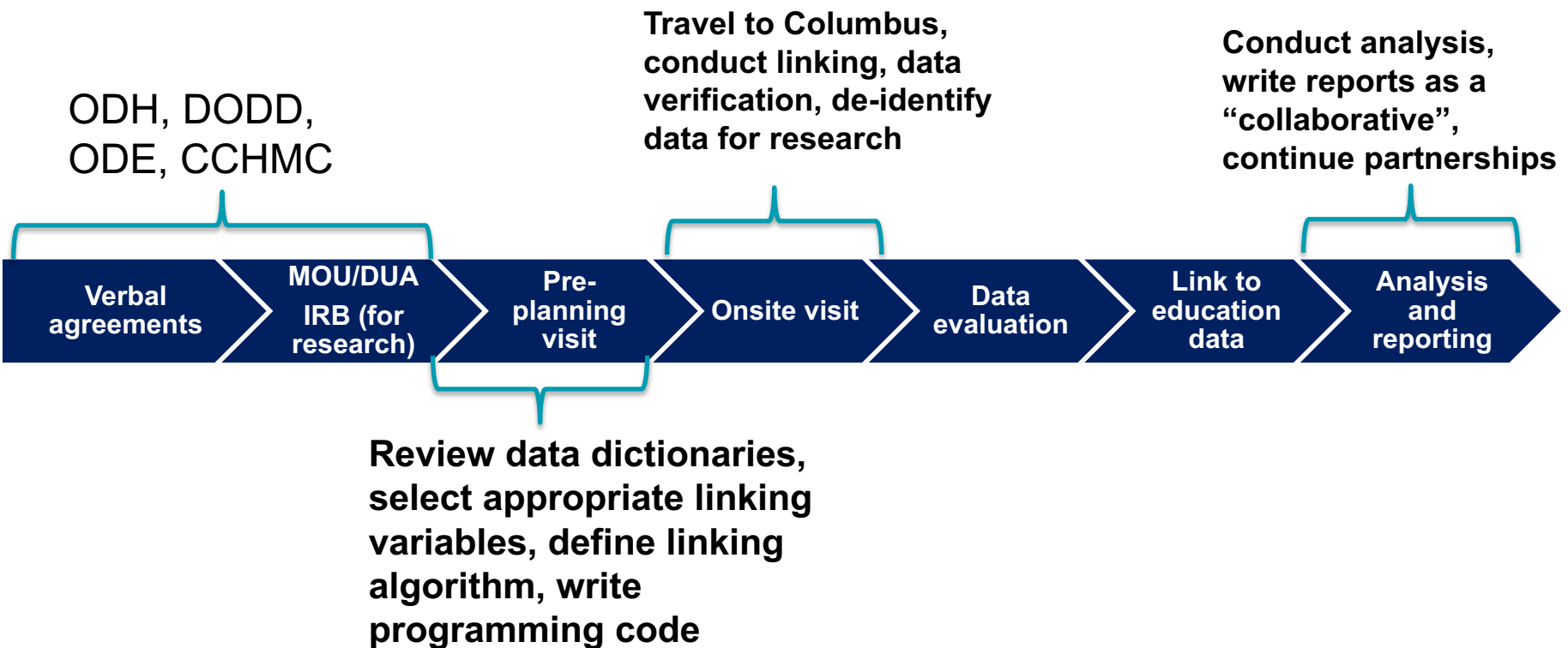
Screening and follow up

Dates, Individualized Family Service Plans information, documented delays, frequency & duration of services, service types, developmental disabilities

course information, late testing, assessments, IEP

System (EMIS)

Process

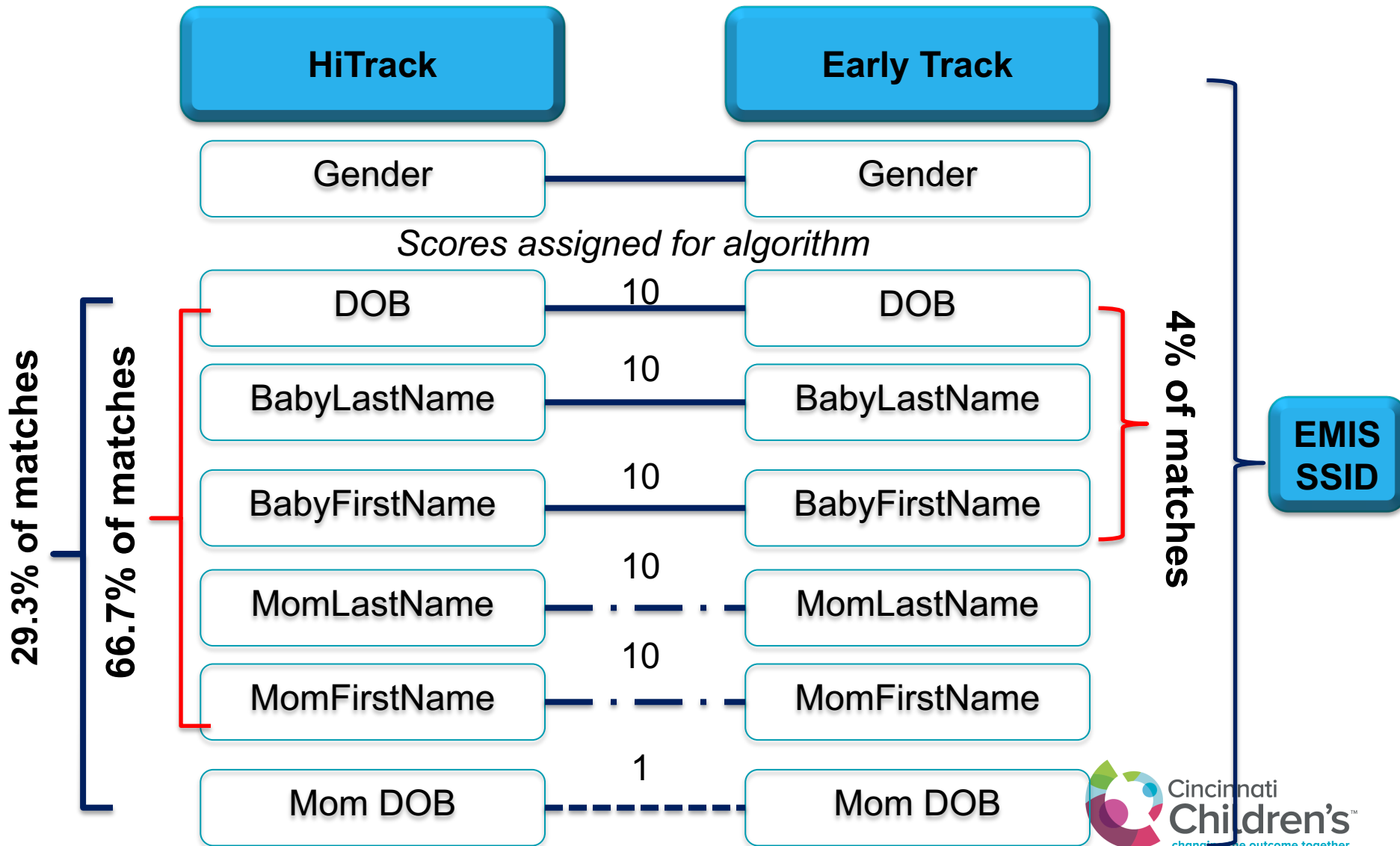


MOU – Memorandum of Understanding; DUA data use agreement

MOA – Memorandum of Agreement

IRB – Institutional Review Board

Linking methods



Actual data catchment of children identified with permanent hearing loss in state of Ohio

HiTrack - ODH

1746 infants

Early Track- DODD

1262 infants/children (72.3%)

502 records linked to ODE records

EMIS

447 students with pre-K

424 Kindergarten

163 1st/2nd grade

484 not
linked



Born between January 1, 2008 through December 31, 2014

Demographic characteristics

	All infants N=1746	linked to EI N=1262	linked to ed N=502
Gender- Male	51.1%	53.7%	56%
Race			
Caucasian	70.3%	75.4%	79.1%
Black/AA	13.1%	12.3%	13.6%
Hispanic	4.6%	4.4%	2.8%
Gest age (wks)	37.4 (3.3)	37.4 (3.3)	37.4 (3.3)
Birth weight (g)	2969 (824)	2972 (828)	2968 (852)
Born Premature	21.7%	22.4%	23.1%
Mom education			
< HS	12.5%	11.7%	11.8%
HS/GED	22.3%	21.5%	23.3%
Some college	27.1%	29.2%	28.9%
College grad	23.7%	27.2%	29.5%
missing	14.4%	10.5%	6.6%

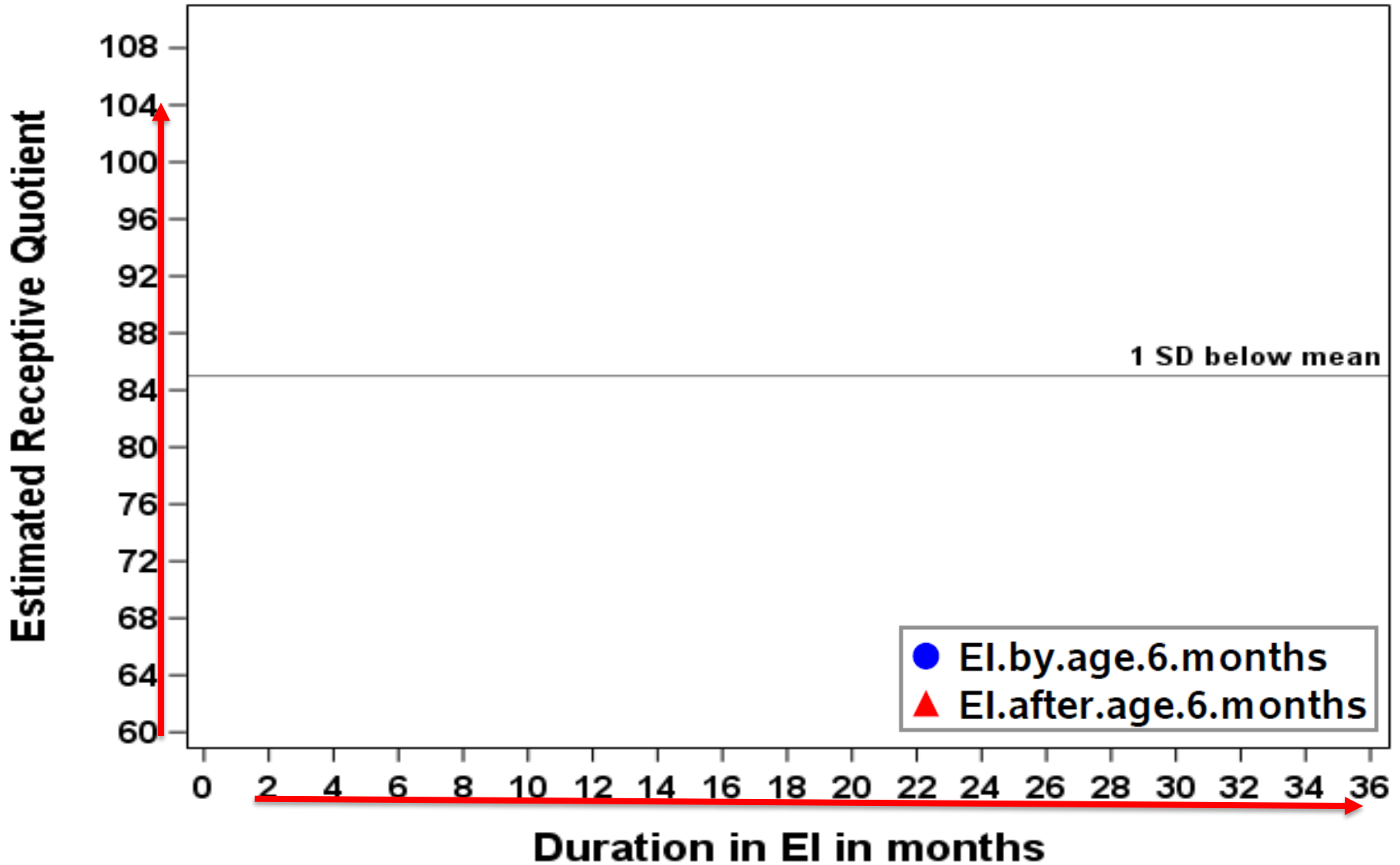
Hearing characteristics

	All infants N=1746	linked to EI N=1262	linked to ed N=502
Median age HL confirmed	3.9 mo (IQR 1.9-9.6)	3.9 mo (IQR 1.9-9.0)	3.9 mo (IQR 1.8-9)
Risk Indicator	38.6%	40.2%	45.6%
Bilateral HL	73.6%	75.6%	76.9%
Degree of loss			
Mild	29.8%	29.6%	30.5%
Moderate	14.8%	15.4%	15.7%
Mod- Severe	12.8%	13.4%	11.7%
Severe	6.6%	6.7%	7.8%
Profound	27.1%	28.6%	25.8%
Diagnosed conditions	----	28%	37.7%
EI by age 6 mo	----	56.5%	59.5%

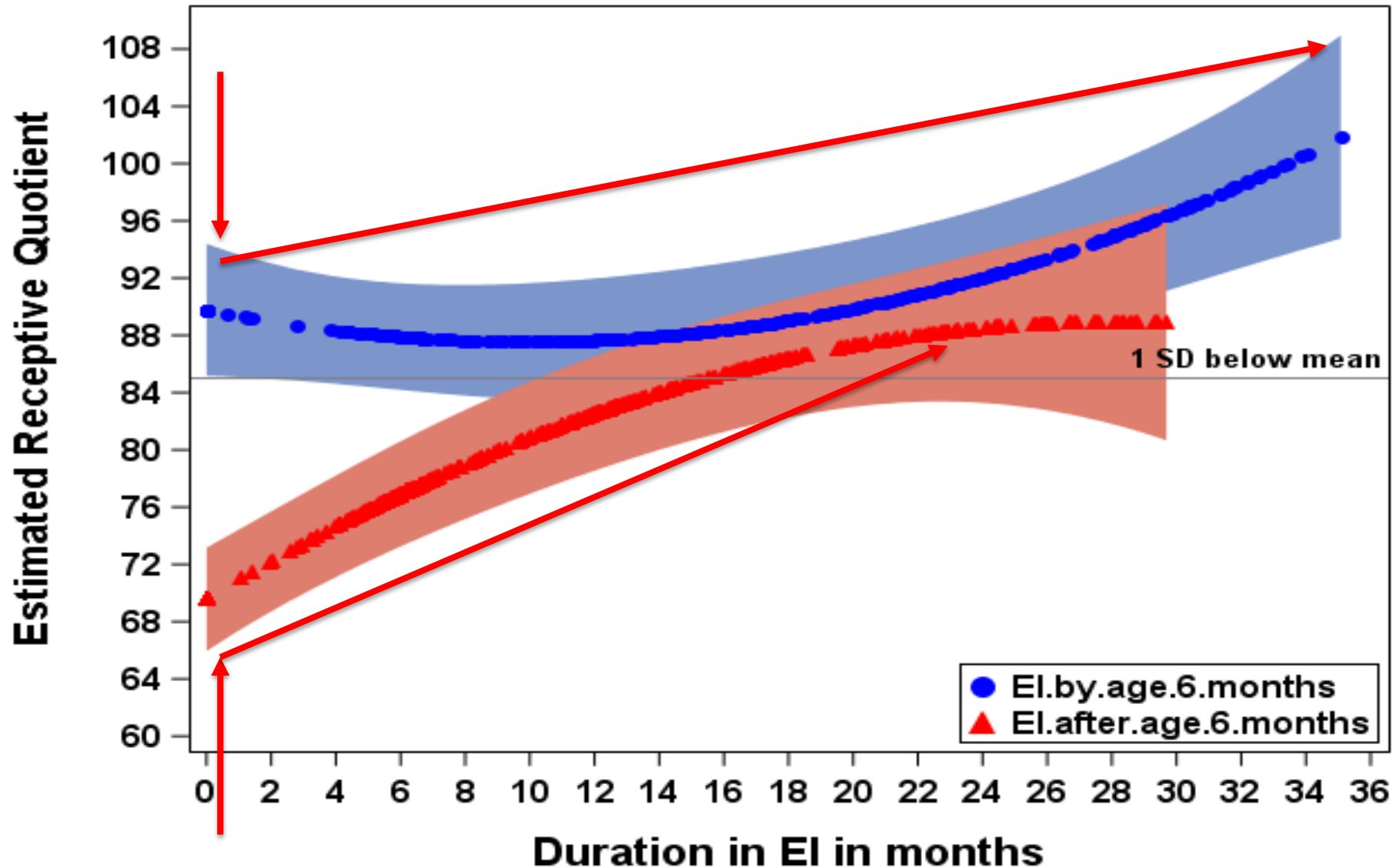
Language outcome

- SKI*HI Language Development Scale (LDS)
 - 6 month intervals
 - Parent/observer report
 - Scored as age-appropriate units
- Language quotient (LQ) calculated
 - Unit completed divided by age-appropriate unit for child at time of assessment
 - Calculated for receptive and expressive language




Language over time by age at EI entry



Language over time by age at EI entry



Factors associated with language development

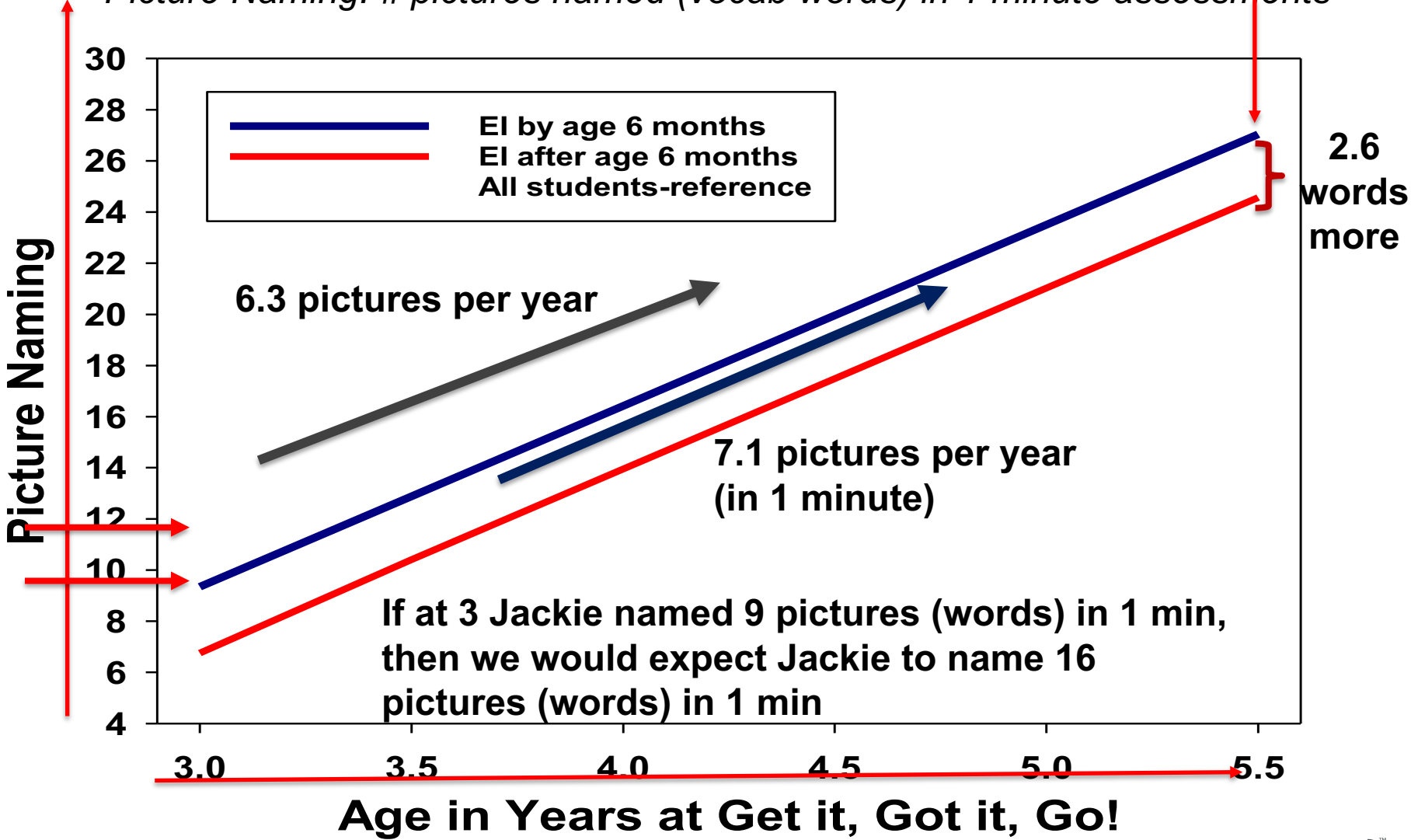
<i>Receptive LQ</i>		Adjusted β	SE	p
EI by age 6 months		18.1	3.2	<.0001
Severe-Prof HL		-10.6	2.7	0.0003
Bilateral HL		-10.8	2.8	0.0001
Presence of disability		-7.8	3.1	0.012
Has risk indicator		-13.5	2.7	<.0001
Mother college ed.		6.5	2.4	0.008
<i>Expressive LQ</i>		Adjusted β	SE	p
EI by age 6 months		20.9	3.2	<.0001
Severe-Prof HL		-9.6	2.6	0.0002
Bilateral HL		-9.8	2.8	0.0005
Presence of disability		-7.9	3.2	0.013
Has risk indicator		-14.2	2.6	<.0001
Mother college ed.		7.9	2.4	0.001

Early Literacy outcomes

- Get it, Got it, Go!
 - Monitors 3 Individual Growth and Development Indicators: **picture naming, rhyming, and alliteration**
 - Brief and standardized administration and scoring procedures
 - Each task is timed
 - Score = number correct (no maximum score)
 - Correlated with Peabody Picture Vocabulary and Preschool Language Scale

Early literacy between D/HH and student-reference

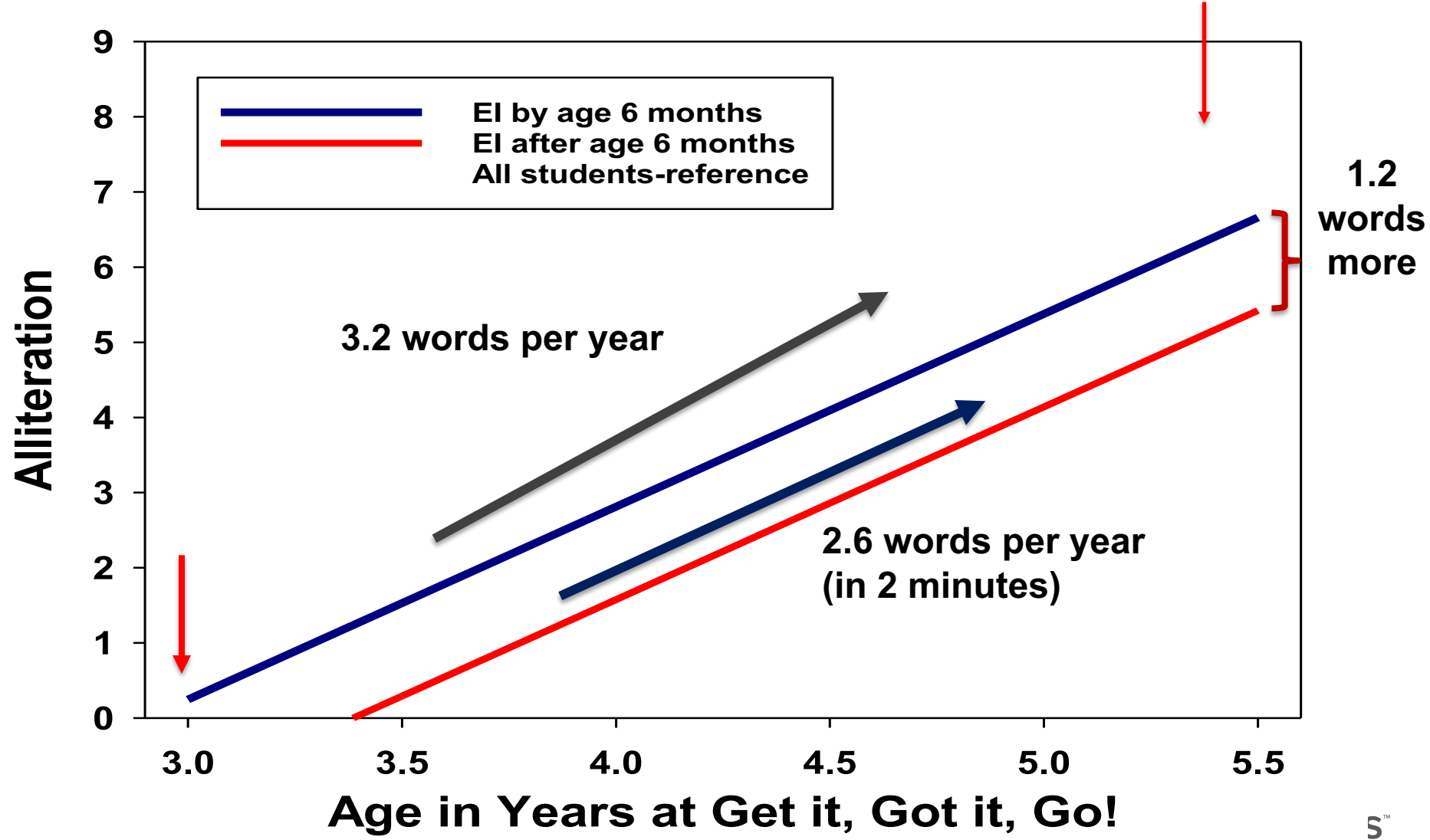
Picture Naming: # pictures named (vocab words) in 1 minute assessments



*after adjusting for confounders

Early literacy between D/HH and student-reference

Alliteration: # words in 2 minute assessments



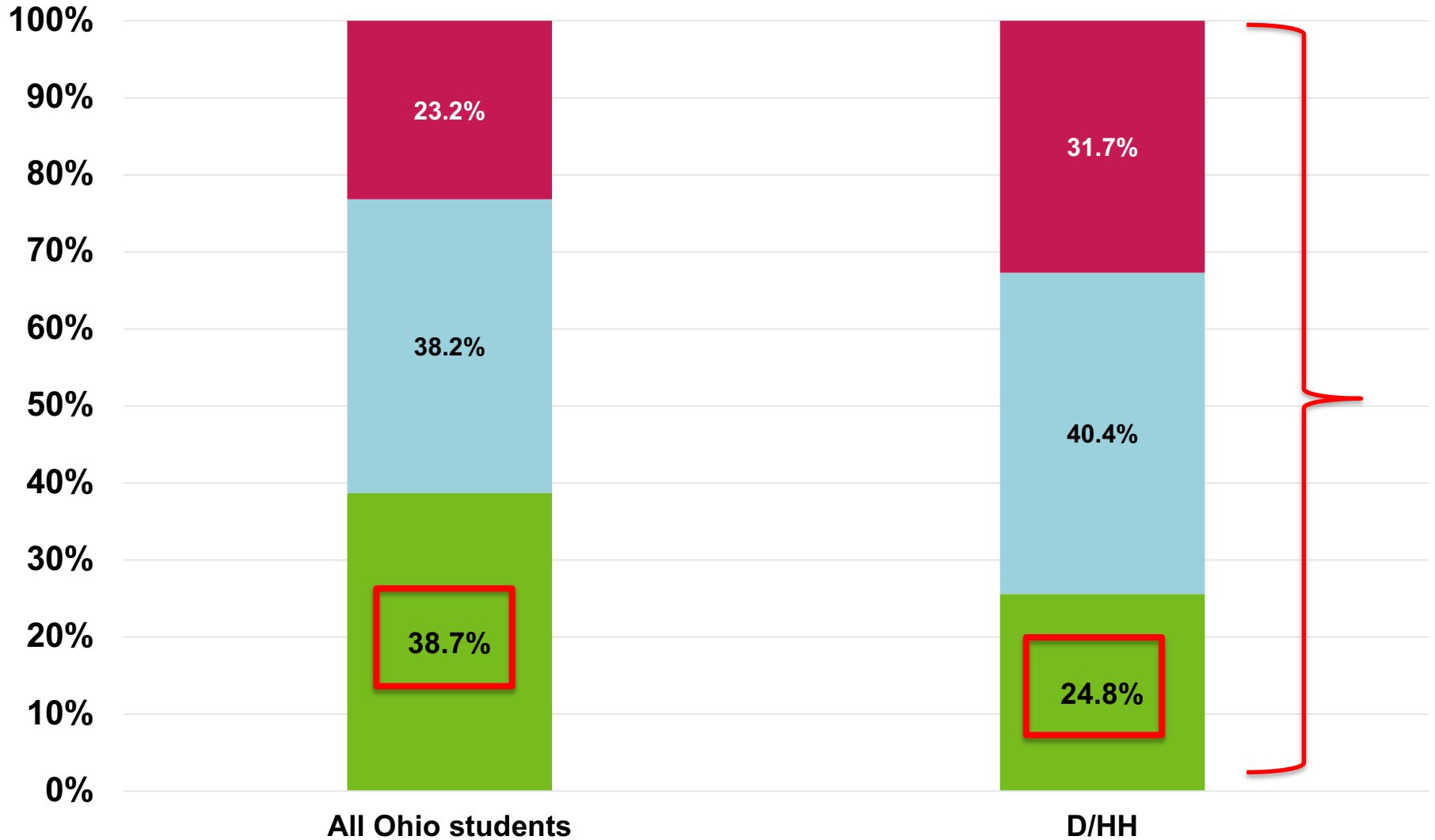
*after adjusting for confounders

Kindergarten Readiness

- Kindergarten Readiness Assessment
 - Language and literacy, mathematics, social foundations, and physical well-being and motor development
 - Demonstrating, approaching, emerging
- *Children assessed at beginning of the year, could be assessed towards end of year*

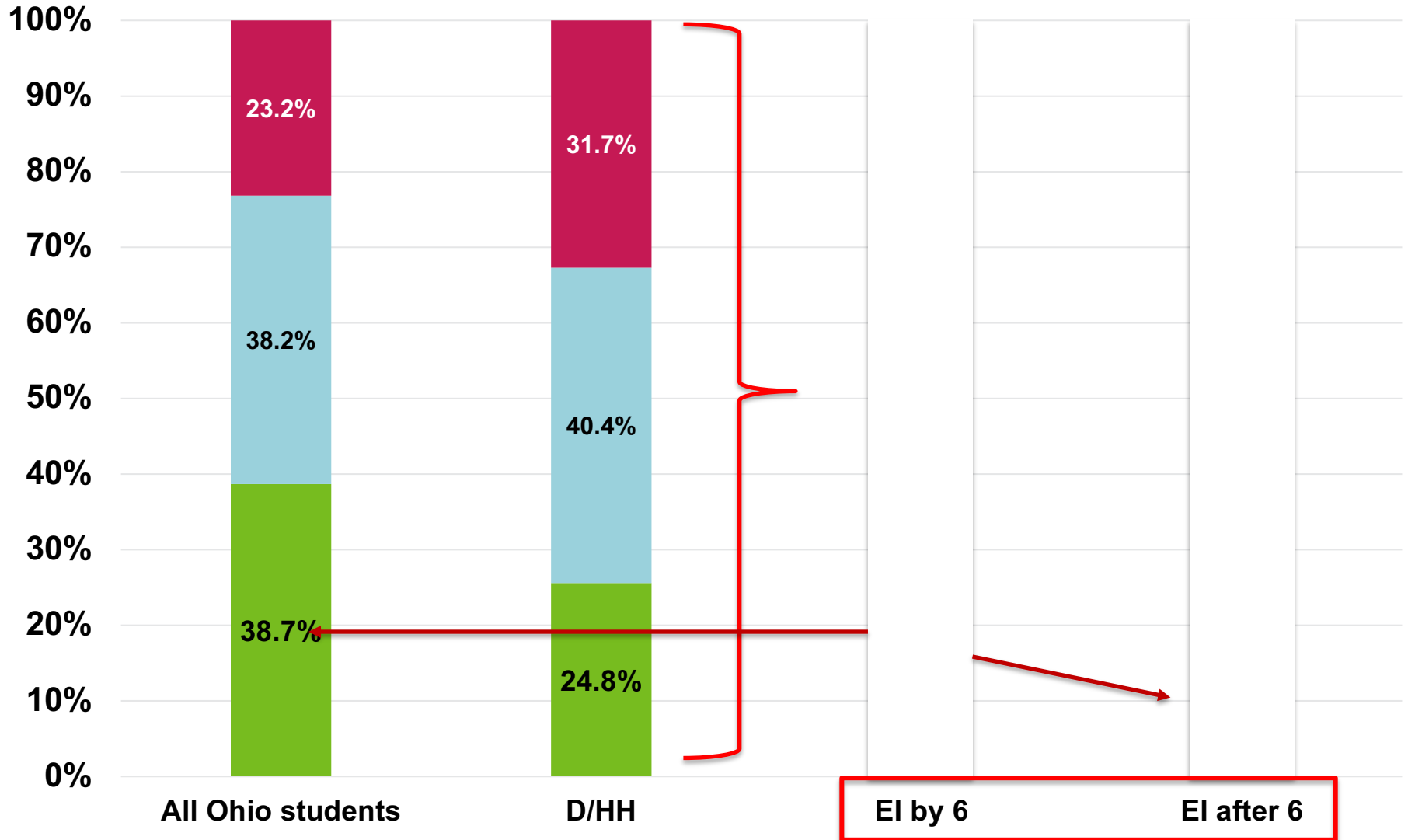
Kindergarten Readiness

■ Demonstrating ■ Approaching ■ Emerging

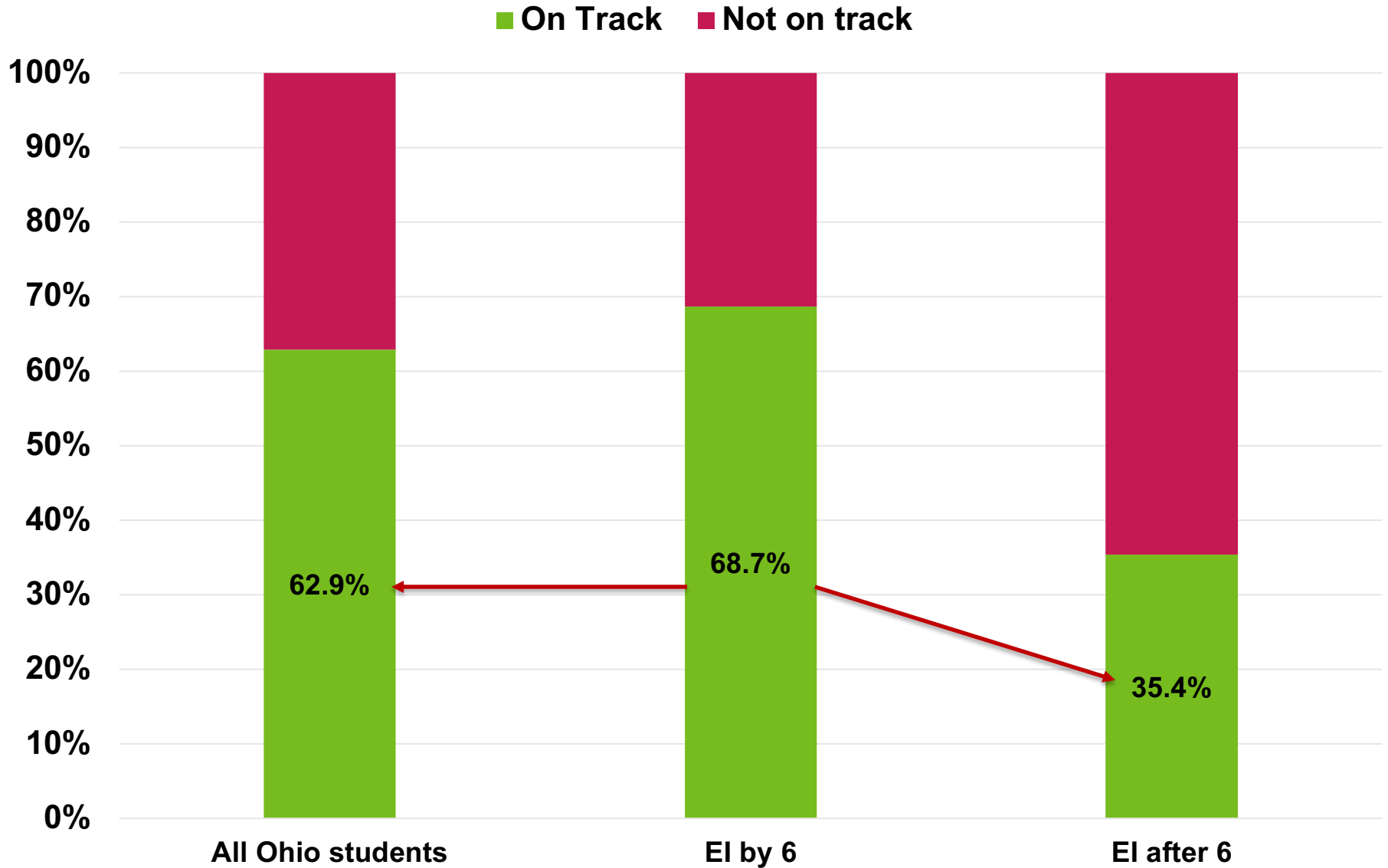


Kindergarten Readiness

■ Demonstrating ■ Approaching ■ Emerging



Language and Literacy “on track”



Future work

- Assess different EHDI benchmark cutoffs
- Evaluating the role that intervention intensity plays in outcomes
- Evaluate longer term educational outcomes
- Understanding children who were referred but not enrolled into EI
- Understanding children in the education system who may not have accessed EI

In Summary

- Earlier intervention (by 6 months of age) is associated with improved language in the first 36 months of life
- Also associated with higher early literacy skills in preschool
 - Evidence of sustained effect of EI and longer term impact of EHDI 1-3-6 benchmarks

Occurred because we had 3 distinct, autonomous, motivated agencies working towards a common goal

In Summary

- Development of a child does not end at Part C, nor does it begin at Part B
- Study supports the importance of linking data systems
- Can also identify areas for improvement regarding transition between EI and preschool/academics

Thank you!!

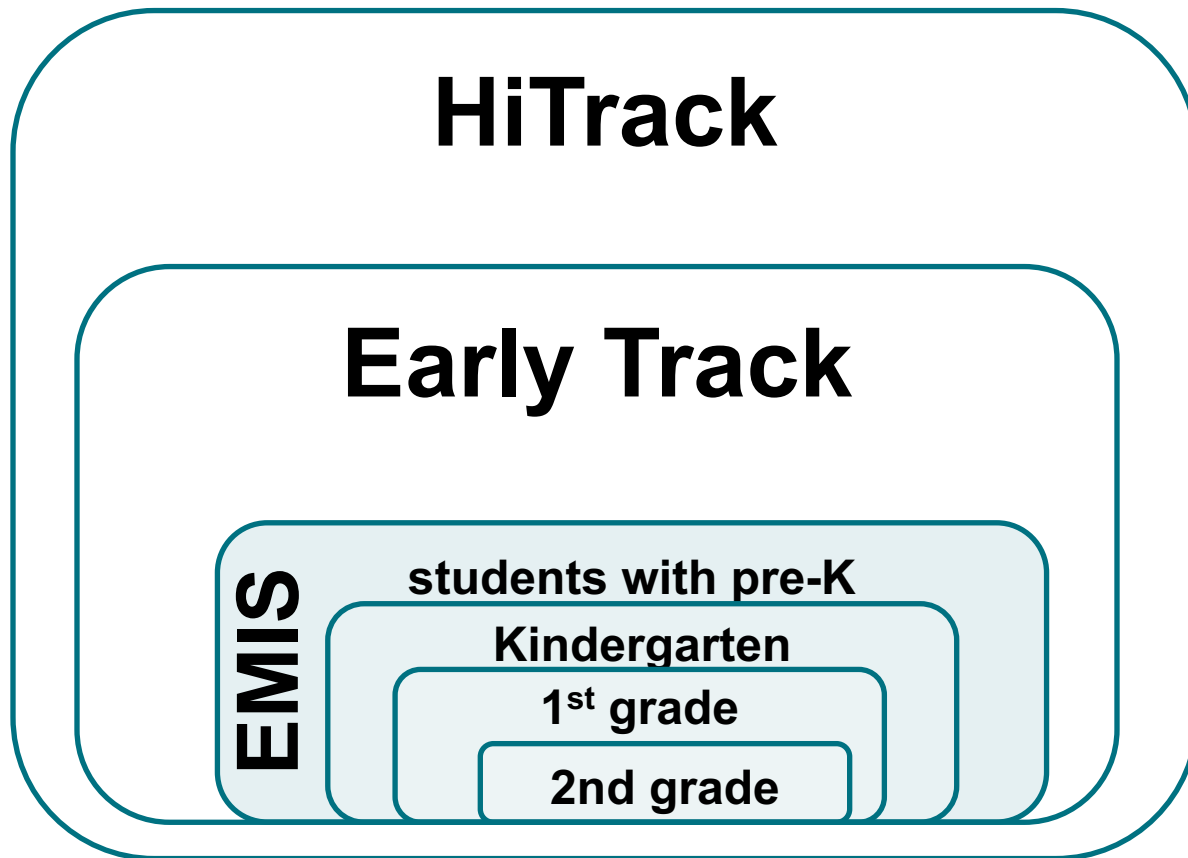
Questions?

Extra Slides

Motivation for Project

- Examine the feasibility of linking large datasets across different governance systems in order to examine the effectiveness of early intervention for hearing loss on important developmental and early academic outcomes
- Provide a “roadmap” for the linkage process that could be:
 - Integrated into Ohio
 - Adopted by other states
- Demonstrate the impact of early intervention for improving long-term outcomes across the entire spectrum of hearing loss and ability

Proposed Data Catchment of Children Identified with Permanent Hearing Loss in State of Ohio



Born between January 1, 2008 through December 31, 2014



Methods

- Data sources
 - Vital Records, HiTrack, Early Track, EMIS
- Included multiple data formats:
 - SAS (HiTrack)
 - Text (Early Track)
 - Excel (EMIS)-linking occurred later
- Linking program utilized SAS Enterprise Guide

Linking Methods [HiTrack – Early Track]

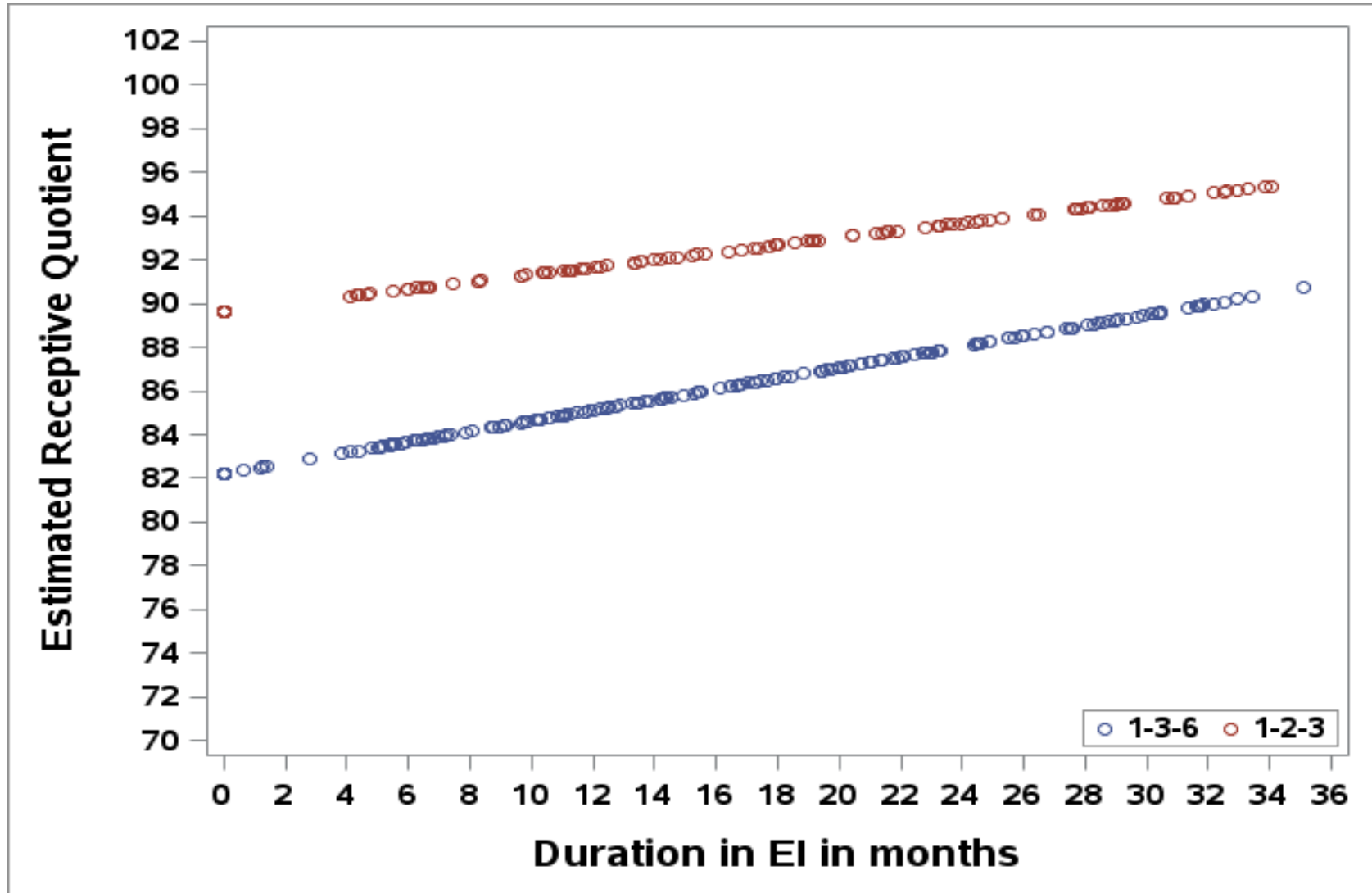
1. Removed all special characters in the infant's and mother's names and changed all the letters to lower case
2. Select records that match:
 - Baby gender and
 - At least one of the following: BABYBIRTHDATE
BABYFIRSTNAME BABYLASTNAME MOTHERFIRSTNAME
MOTHERLASTNAME MOTHER_DOB
3. Create scoring system:
 - a) Select those records that have a perfect match
 - b) Select records that match all except the MOTHER_DOB
 - c) Finally select records that match on whole baby info (last name, first name and DOB).

***Applied strict linking methods – sought for perfect baby match
Some manual verification was necessary***

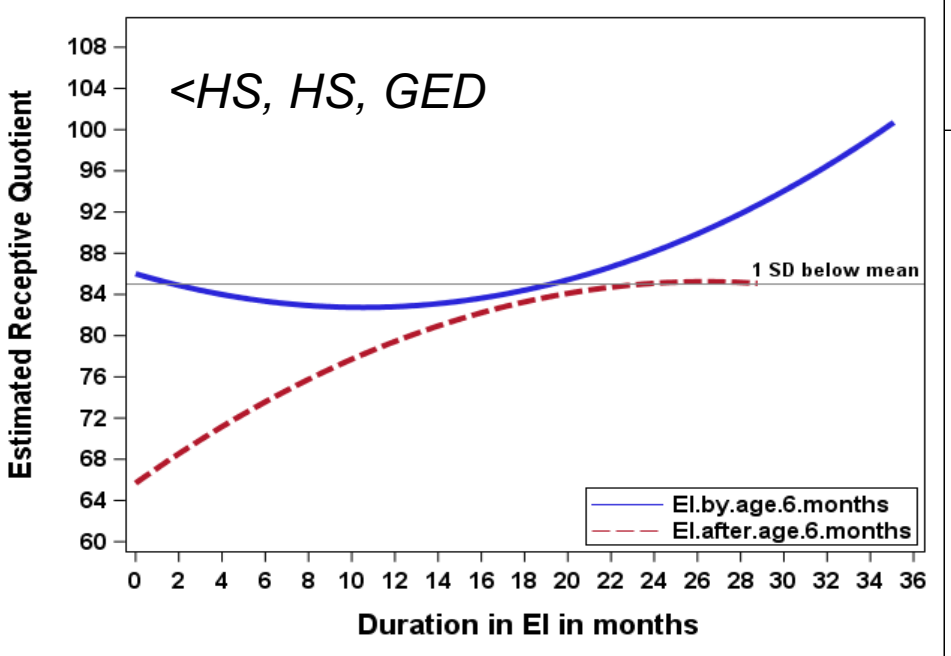
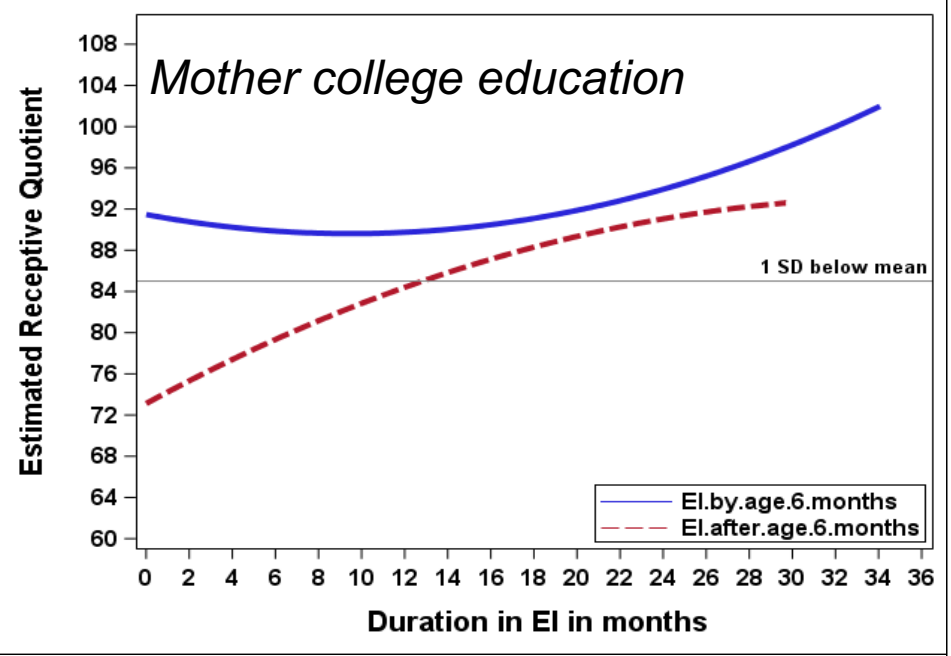
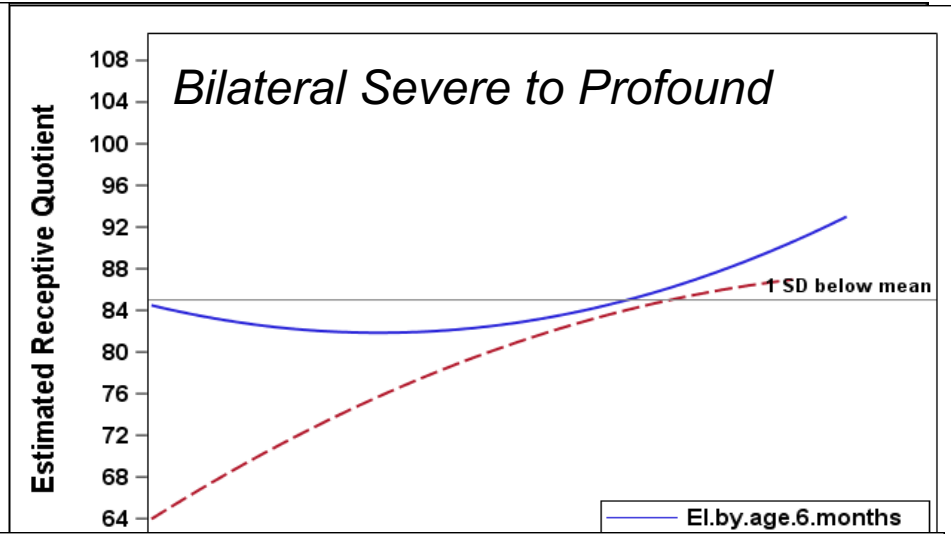
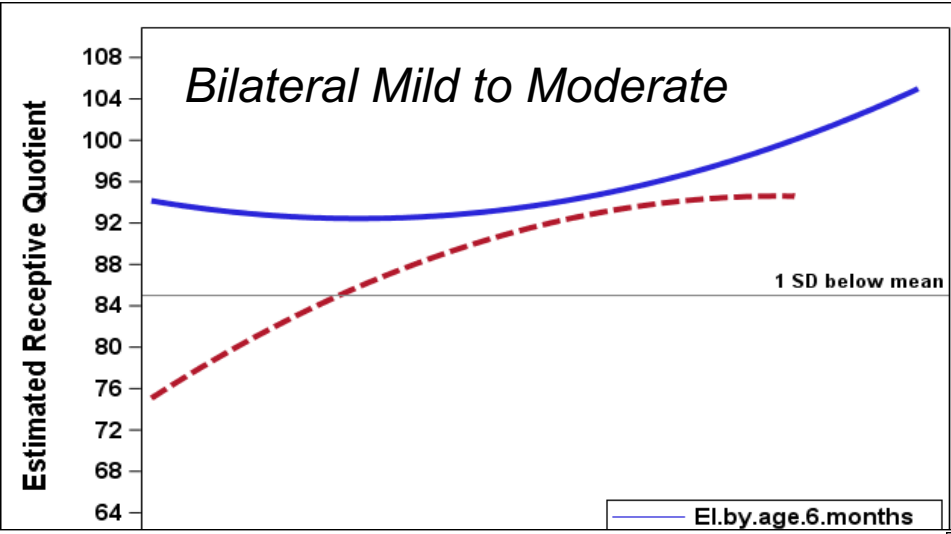
Outcomes

- Language Assessments
 - SKI*HI Language Development Scale
- Preschool Assessments
 - Get it, Got it, Go! [*Early literacy*]
 - picture naming, rhyming, alliteration
 - Early Childhood Outcome Assessment
 - SE skills, acquiring/using knowledge and skills, taking appropriate action to meet needs
 - ASQ/SE [*Social-emotional measure*]
- Kindergarten Assessments
 - Kindergarten Readiness Assessment
- Early Learning Assessment
 - awareness & expression of emotion, cooperation with peers, phonological awareness, communication, coordination, safety-injury prevention, relationships with adults, vocab, numbers, personal care

By EHDI Benchmarks



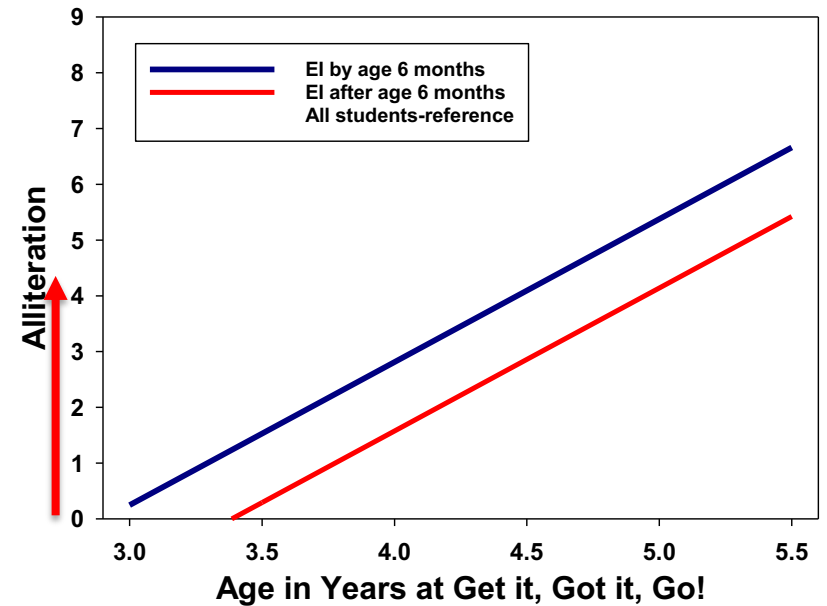
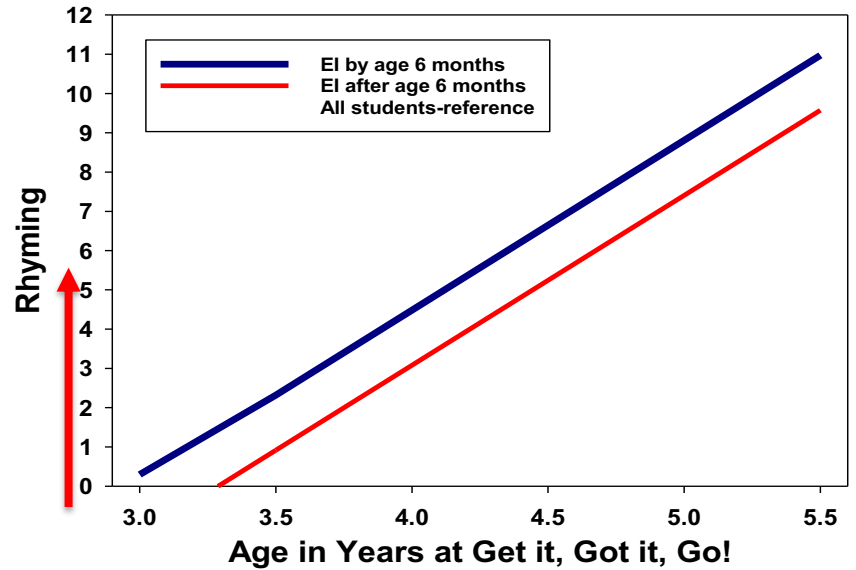
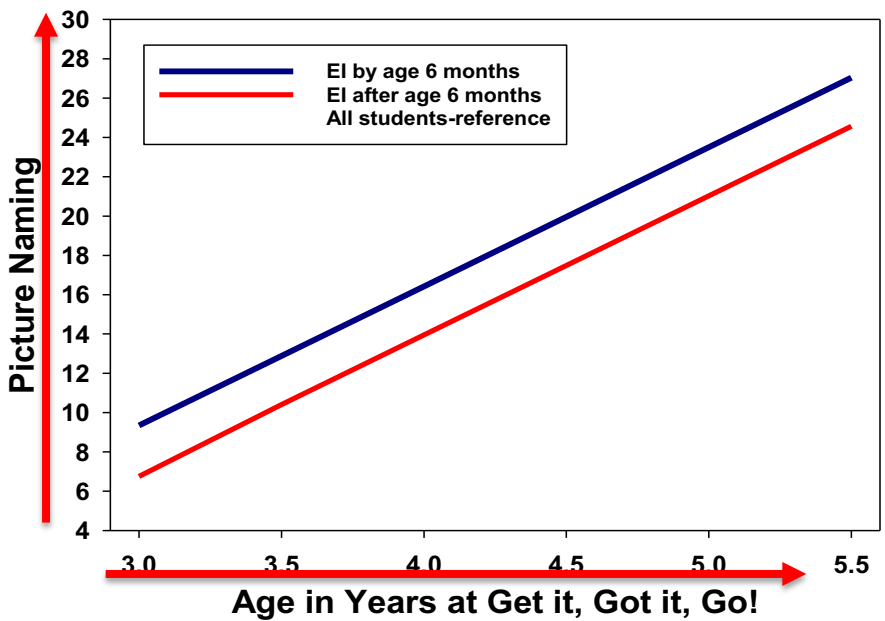
Language over time by age at EI entry



Factors associated with early literacy

<i>Picture naming</i>	Adjusted β	SE	p
Age (in years)	7.1	0.4	<.0001
EI by age 6 months	2.6	0.9	0.006
Severe-Prof HL	-2.5	1.0	0.014
Presence of disability	-4.8	1.1	<.0001
Mother college ed.	3.4	1.0	0.0004
<i>Rhyming</i>	Adjusted β	SE	p
Age (in years)	4.3	0.5	<.0001
EI by age 6 months	1.5	0.8	0.04
Mother college ed.	1.7	0.7	0.02
<i>Alliteration</i>	Adjusted β	SE	p
Age (in years)	2.6	0.32	<.0001
EI by age 6 months	-1.2	0.5	0.009

Early literacy outcomes using *Get it Got it Go*



Comparison of early literacy between D/HH and student-reference

<i>Picture naming*</i>	D/HH	All students-ref
Word increase each year	7.1	6.3
EI by age 6 months	2.6	----
<i>D/HH start with fewer words</i>		

<i>Rhyming*</i>	D/HH	All students-ref
Word increase each year	4.3	4.4
EI by age 6 months	1.5	----

D/HH start at same place

<i>Alliteration*</i>	D/HH	All students-ref
Word increase each year	2.6	3.2
EI by age 6 months	1.2	----

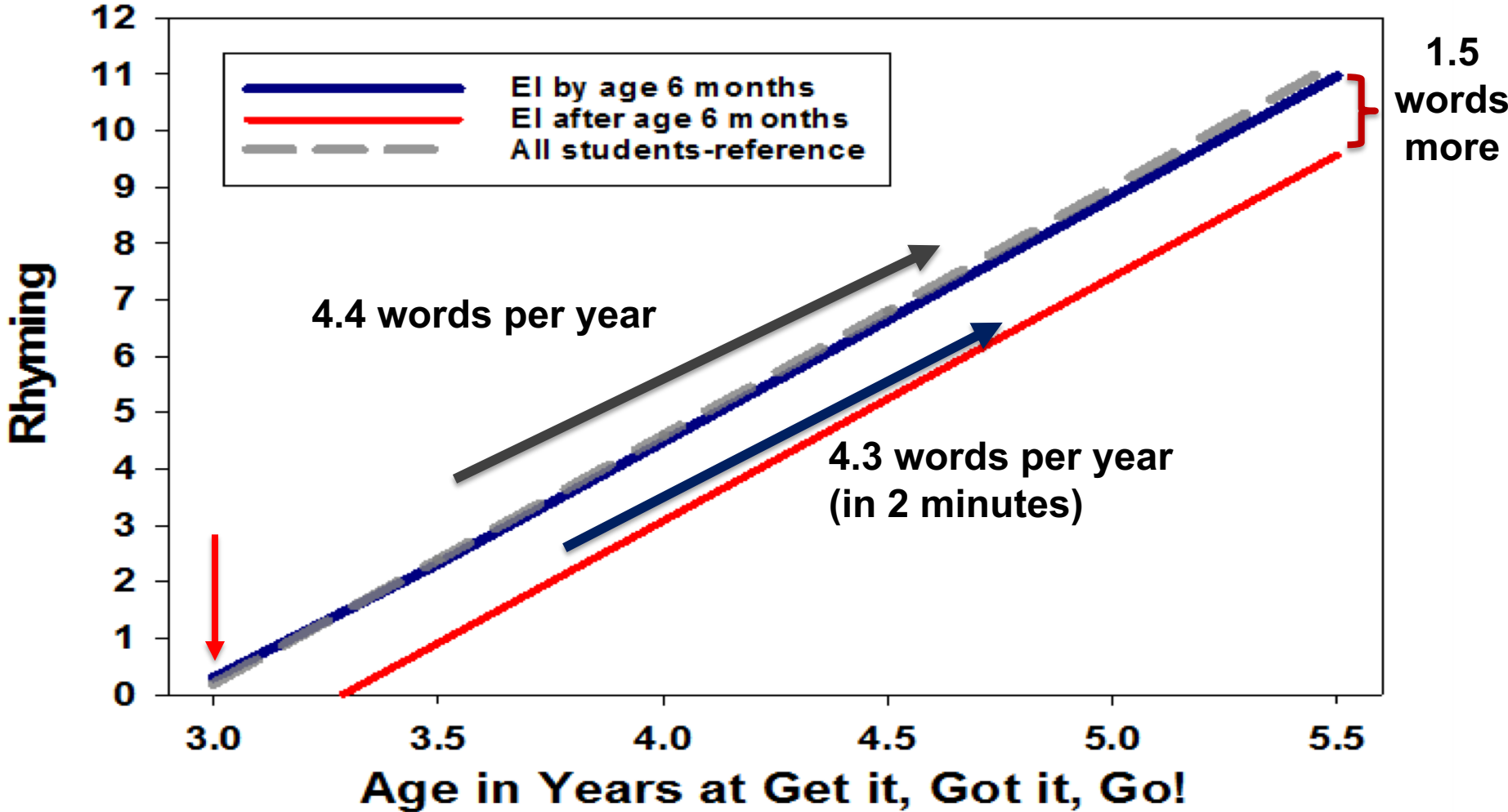
D/HH start at same place

**after adjusting for confounders*



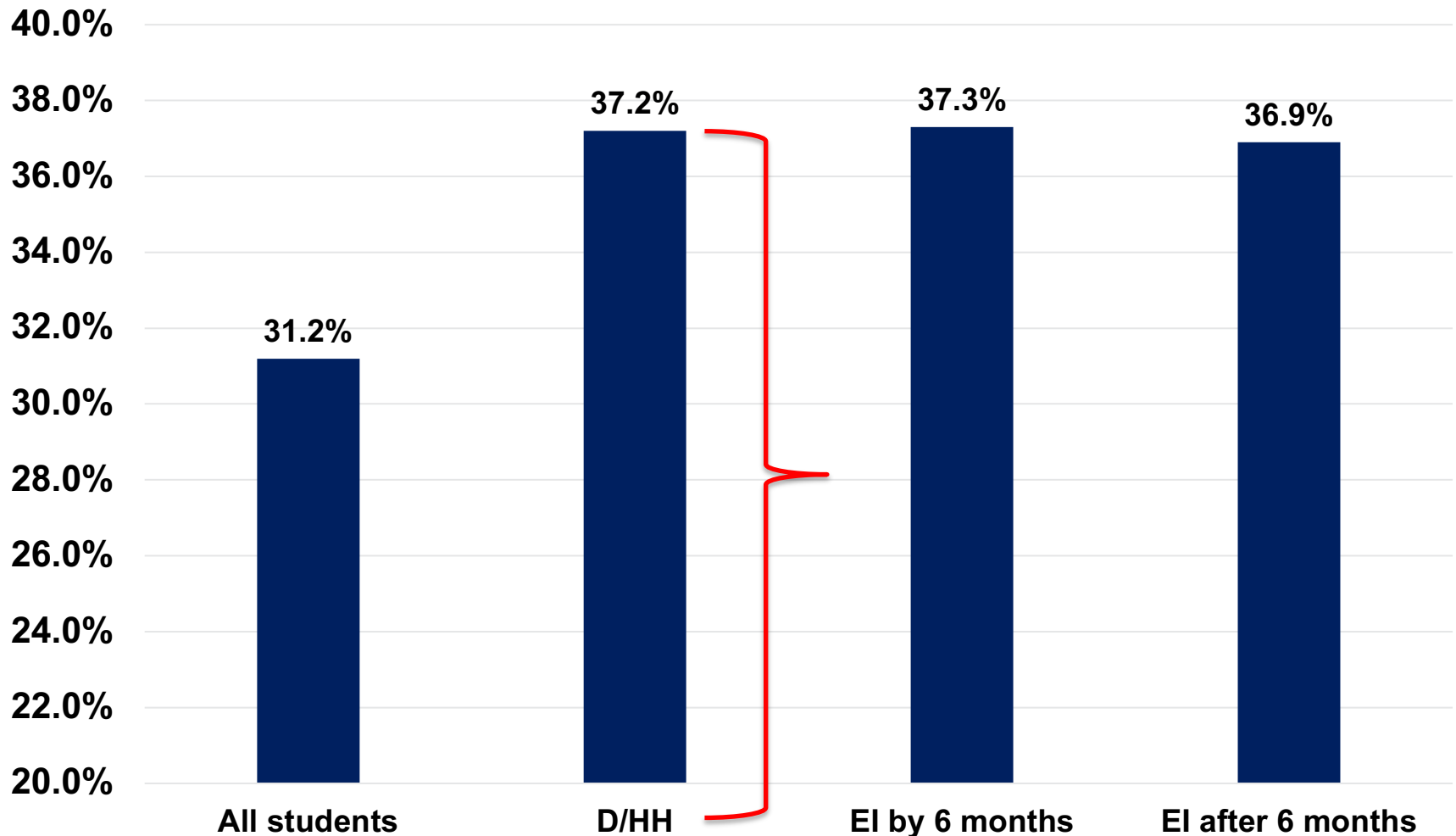
Early literacy between D/HH and student-reference

Rhyming: # words in 2 minute assessments



*after adjusting for confounders

Percent of children with social emotional concerns



Successes

- **3 distinct, autonomous agencies partnering**
 - Very motivated = great partnerships
- Our linkage results mirrored what we expected
 - Proportion of infants served in EI similar to what we found
- Early results indicate that children served in early intervention have improved outcomes
 - The earlier the intervention takes place, the better the outcomes
 - The impact of EI appears to extend into school years

Early Challenges

- **System changes – EI for DHH moved from ODH oversight to DODD oversight**

Solution: enhanced communication, patience, persistence, motivation of partners at ODH, DODD, ODE and invested interests

- Agreements and IRBs across agencies took time (each agency had separate legal depts)

- Data sit in silos

- “Ownership” with corresponding agencies
- Systems not linked
- No uniform identifiers that automatically align all 3 data systems

Solution: Motivation of partners, included methodologists with experience in linking data systems

Some Linkage Challenges

- Used an algorithm that required a perfect baby match
 - Following a strict algorithm potentially misses infants
 - *Solution: Additional manual verification of infants believed to have received EI*
 - *Could also apply layered algorithms for high level matching*
- Special populations may requiring additional attention
 - Transient, non-residents/moving residents
 - *Solution: Improve documentation*
- Mother's data could be problematic
- Team traveled to conduct the linkage
 - Only due to the IRB restrictions in place
 - Not necessary for public health purposes

Some Linkage Challenges

- Most records in HiTrack did not include mother's DOB
 - Ended up not being an important factor
- Different mother's names (first or last name inverted or misspelled)
 - Manual review, however, was minimal
- Different person altogether as primary care provider
 - Need to verify address perhaps

Why is this important?

- Partnerships and innovative data linkages across 3 state systems can serve as a model
 - For other state EHDI programs
 - For the broader population of children served in Early Intervention (EI)
- Provides a means to address relevant and important topics regarding short & long-term outcomes of EI services

Would You Have Done Anything Different?

- Perhaps would have done more pre-work for link visit
 - Protocolized specific steps for all parties involved for the on-site visit
 - May have streamlined the work on the day of the visit
- Expanded my scope of interest regarding questions pertaining to education
 - Rich source of data