

# EARLY INTERVENTION UNDER I.D.E.A.

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ACCESS, SERVICES, AND OUTCOMES FOR  
INFANTS AND TODDLERS WITH OR AT RISK  
FOR DEVELOPMENTAL DELAYS

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# BACKGROUND

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# Data sources\*

- National surveys (e.g., National Health Interview Survey, National Children's Health Survey, U.S. Census)
- Federally-funded nationally representative longitudinal studies (e.g., Early Childhood Longitudinal Study, National Early Intervention Longitudinal Study)
- Research literature
- State accountability data under IDEA
- Research in progress

*\*References are included at the end of the presentation*

# Historical context

- 1935 The Social Security Act
- 1964 Economic Opportunity Act / Head Start
- 1975 Education of All Handicapped Children Act
- 1986 Amendments to EAHC: “PART C”
- 1990 Americans with Disabilities Act
- 1991 Public Health Services Act / Healthy Start
- 1991 Individuals with Disabilities Education Act
- 2000 Children’s Health Act / Healthy Start
- 2004 Reauthorization of IDEA

# Mandated components of Part C EI

- Implementation of a system of early identification and referral (“child find”)
- Evaluation of infants and toddlers in 5 domains
- Development of an Individualized Family Service Plan (IFSP)
- Service provision in the child’s “natural environment” to the maximum extent possible

# At states' discretion

- Which agency serves as the Lead Agency
- Service delivery and administrative models
- Eligibility criteria for participation

# IS EARLY INTERVENTION EFFECTIVE?

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# Effectiveness of Early Interventions

- Hwang et al., 2013: RCT of routines-based EI for children with or at risk for DD
- Roberts & Kaiser, 2015: RCT of an early intervention for toddlers with language delays
- Dawson et al., 2010: RCT of a comprehensive intervention (the Early Start Denver Model) for toddlers with autism spectrum disorder
- Ryberg, 2015: Systematic review of evidence on the Early Start Denver Model for toddlers with autism spectrum disorder (2 RCTs, 4 controlled trials, 2 observational cohort studies)



# Effectiveness of Part C EI

- 1993 - Government Performance and Results Act (GPRA) identified desired outcomes for federally funded programs
- 2002 - Office of Management and Budget (OMB) rated the Part C program as ***“results not demonstrated”***
- 2005 – Implementation of the State Performance Plan which requires states to report results for children who received EI services through Part C

# Reporting requirements for Part C

- Results must be reported annually in three “outcome areas:”
  - “Positive social-emotional skills (including social relationships)”
  - “Acquisition and use of knowledge and skills (including early language/communication)”
  - “Use of appropriate behaviors to meet their needs”
- For each outcome area, results must be reported as the % of children exiting Part C who:
  - ***made “substantial” progress (in that outcome area)***
  - ***were within age expectations (in that outcome area) by the time they exited the program***

PREVALENCE OF  
DEVELOPMENTAL DELAYS  
VS.

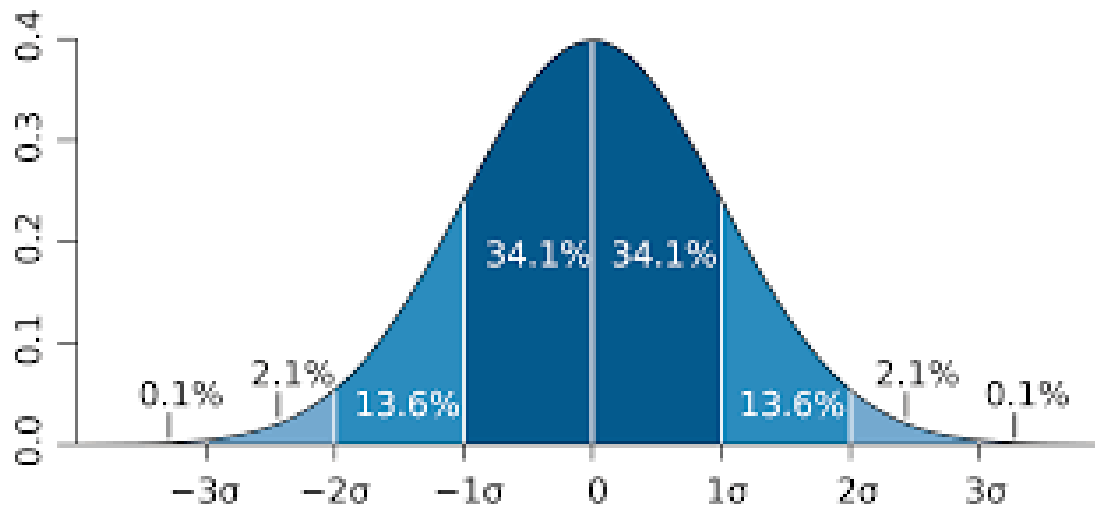
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PERCENT OF THE BIRTH-TO-THREE  
POPULATION SERVED  
IN PART C EI

# Prevalence of developmental delays

- Boyle et al., 2011: Nationally representative sample from the National Health Interview Study, 1997-2008,  $n = 119,367$ . The prevalence of DD in children ages 3-17 was 1 in 6, or approximately **16.6%**.
- Valla et al., 2015: Norwegian clinical sample,  $n = 1,555$ , screened at 4, 6, & 12 months. Using ASQ and a cut-point of  $<-2.0$  SD, the prevalence of suspected DD was **10.3-12.3%**.
- Rosenberg et al., 2008: Nationally representative sample from the Early Childhood Longitudinal Study,  $n = 8,950$  infants and toddlers assessed at 9 and 24 months, the prevalence of DD (at least one domain score  $\leq -1.5$  SD) was approximately **13%**.

# What percent of children have a developmental delay?



# Children served in EI: U.S. & Florida

CHILDREN SERVED IN EI AND PREK DISABILITIES PROGRAMS AS A PERCENT OF THE BIRTH-TO-THREE POPULATION				
Age Group	Florida (%) 2011	Florida (%) 2012	Florida (%) 2013	U.S. (%) 2013
<i>Birth to 1</i>	0.71	0.71	0.75	1.12
<i>1 to 2</i>	1.71	1.69	1.79	2.70
<i>2 to 3</i>	3.26	3.26	3.58	4.71
<i>Birth to 3</i>	1.89	1.89	2.04	2.85
<i>3 through 5</i>	5.68	5.71	5.76	6.16

# Children served in EI: U.S. & Florida

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	<b>US (Scarborough et al., 2006) <i>N</i> = 3,338</b>	<b>North Dade Early Steps (Elbaum et al., in progress) <i>N</i> = 1,513</b>
<b>Diagnosed condition</b>	<b>21.6%</b>	<b>22.9%</b>
<b>Developmental delay</b>	<b>61.7%</b>	<b>77.1%</b>
<b>At risk for DD</b>	<b>16.7%</b>	<b>--</b>

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# ELIGIBILITY FOR EI

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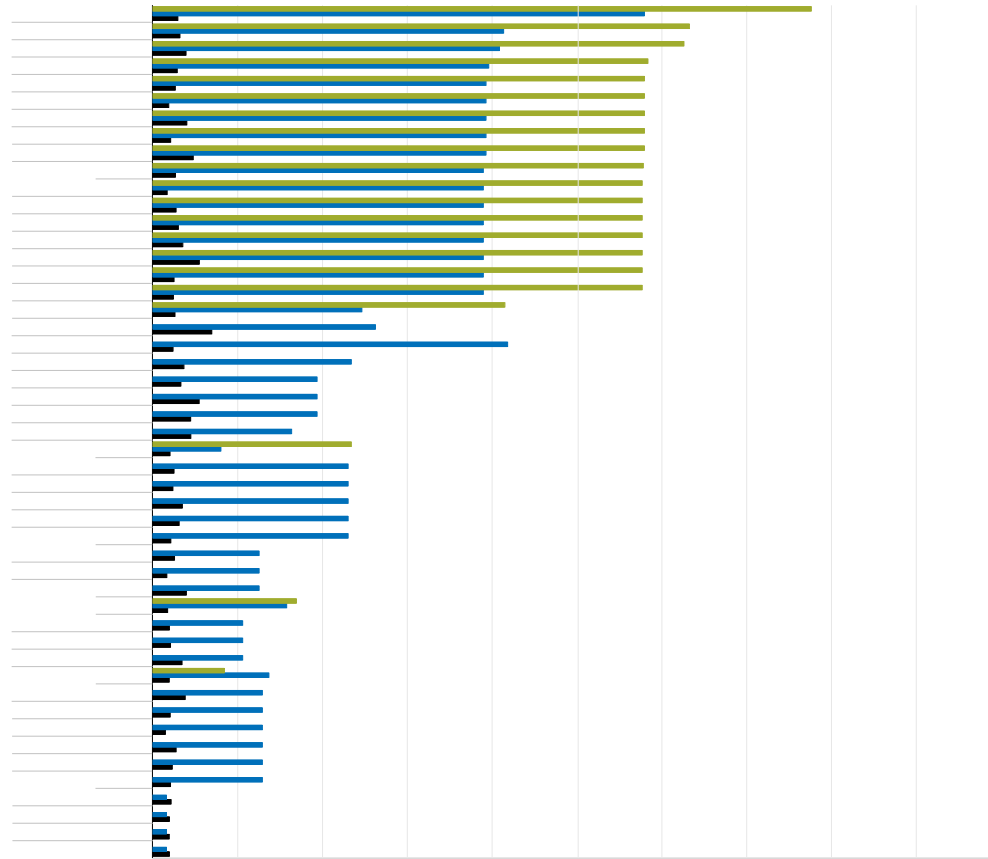
# Variation in states' eligibility criteria for EI

*Among the 48 states that utilize a numerical definition of developmental delay, there are currently over 20 unique eligibility formulas in use (Rosenberg, Robinson, Shaw & Ellison, 2013).*

## ITCA Categorization of States by Eligibility Criteria

	BROAD	MODERATE	NARROW
2002	55%	29%	16%
2014	30%	41%	29%

# % presumptively eligible vs. % served (Rosenberg et al., 2013)



# Eligibility criteria for EI in Florida

- *Through June 2010:*
- A delay of  $-1.5$  *SD* in any one (of five) developmental domains: social-emotional, communication, cognitive, motor, adaptive
- *Beginning July 2010:*
- A delay of  $-2.0$  *SD* in any one domain, or a delay of  $-1.5$  *SD* in any two or more domains.

# THE SERVICE “FUNNEL”

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# Use of developmental screening

- American Academy of Pediatrics, 2006
  - Policy statement recommending developmental screening of all children birth to 3 as a routine part of well-child care
- National Survey of Children's Health, 2011-12
  - Investigated the percent of children aged 10 months to 5 years who received a standardized screening for developmental or behavioral problems
  - **24.0% in Florida vs. 30.8% nationally**

# Screening increases referral and access

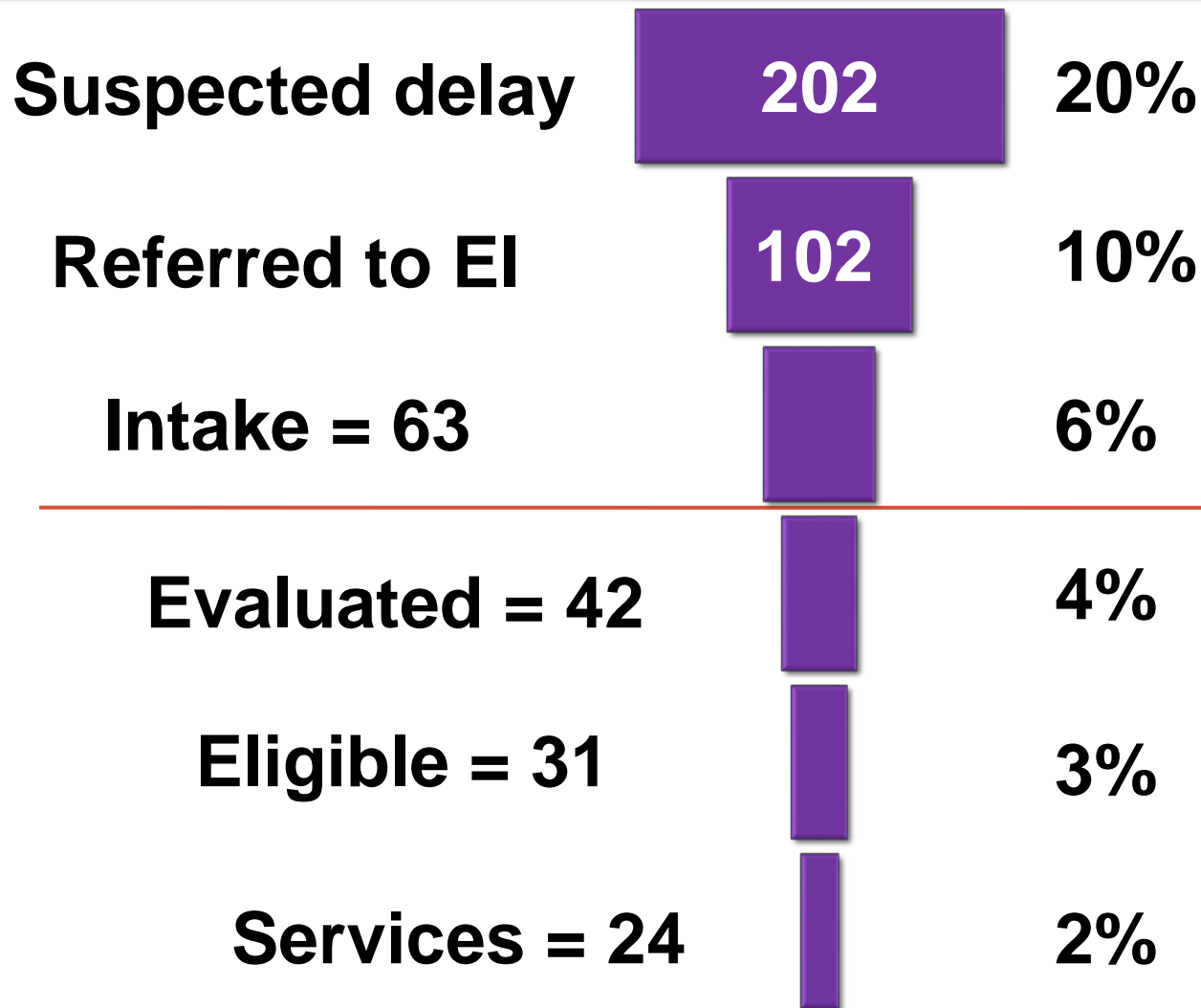
- Guevara, Gerdes, Localio, Huang, et al., 2013
- $N=2103$  children < 30 months, 3 arms:
  - Developmental Screening (ASQ-II and M-CHAT) *with office staff assistance*
  - Developmental Screening *without office staff assistance*
  - Surveillance only

	<b>Developmental Screening <i>with office staff assistance</i></b>	<b>Developmental Screening <i>without office staff assistance</i></b>	<b>Surveillance</b>
<b>% identified with delays</b>	<b>23.0</b>	<b>26.8</b>	<b>13.0</b>
<b>% referred to EI</b>	<b>19.9</b>	<b>17.5</b>	<b>10.2</b>
<b>% determined eligible for EI</b>	<b>7.0</b>	<b>5.3</b>	<b>3.0</b>

# But screening is not sufficient to ensure access

- Screening
  - Referral
    - Intake
      - Evaluation
        - Eligibility determination
        - IFSP development
        - Services

# Of $N = 1034$ children screened:



*Kavanagh, Gerdes, Sell, Jimenez, & Guevara (2012)*



# The identification-to-services funnel in three states

- The study used 2008 birth cohort data from 3 states: FL, MS, & CT
- Florida births 237,417
- Mississippi births 44,904
- Connecticut births 38,499

*Elbaum et al., 2013*



# 2008 Florida Births 237,417



Referred  
to Part C

**24,912**

Evaluated  
for Eligibility

**18,403**

Eligible for Part C

**12,387**

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Initial IFSP Developed

**12,387**

Services Started

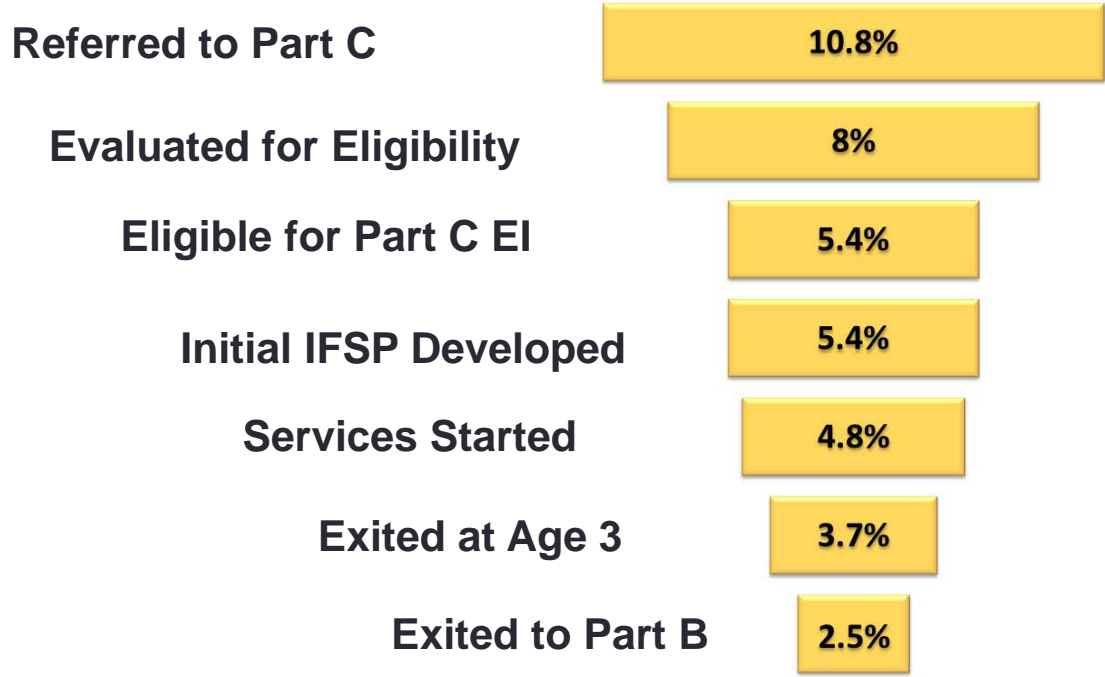
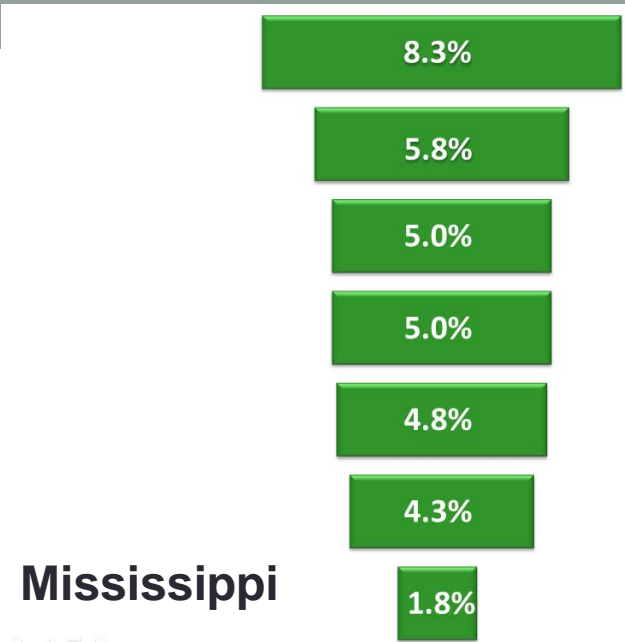
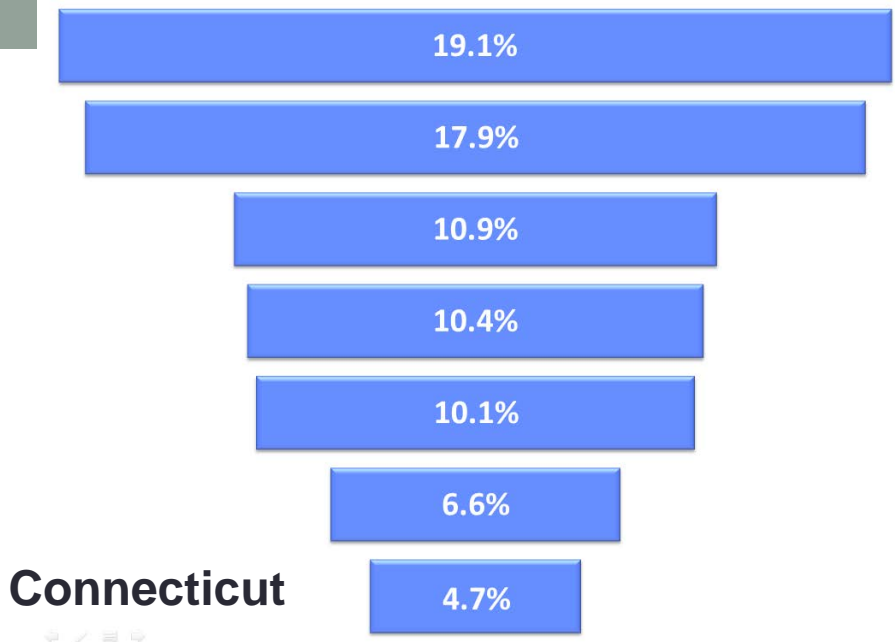
**11,183**

Exited at Age 3

**8546**

Exited to Part B

**5697**



Florida's  
2008  
birth cohort

# EVALUATING OUTCOMES OF PART C EI

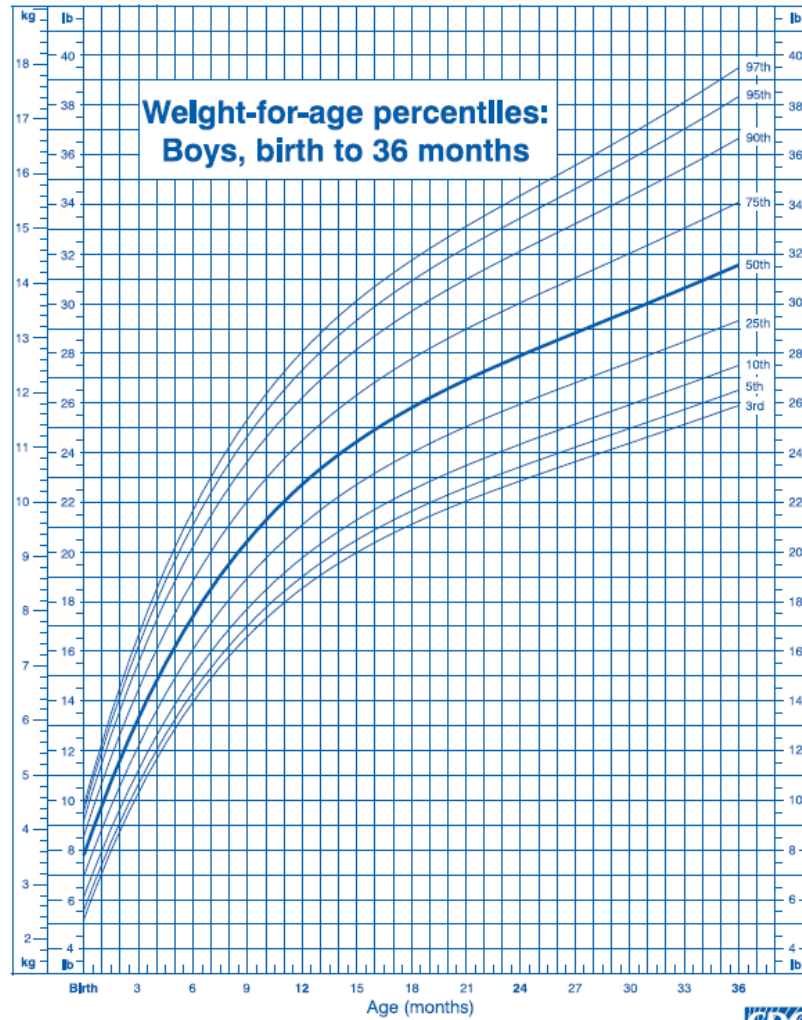
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- \*Children's progress between entry and exit
- \*Developmental functioning on exit (usually at age 3)

# EXPECTED PROGRESS

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- For typically developing children
- For children with specific conditions or delays



Published May 30, 2000.

SOURCE: Developed by the National Center for Health Statistics in collaboration with the National Center for Chronic Disease Prevention and Health Promotion (2000).



Figure 1. Individual growth chart 3rd, 5th, 10th, 25th, 50th, 75th, 90th, 95th, 97th percentiles, birth to 36 months: Boys weight-for-age

# Growth charts

## Observed data

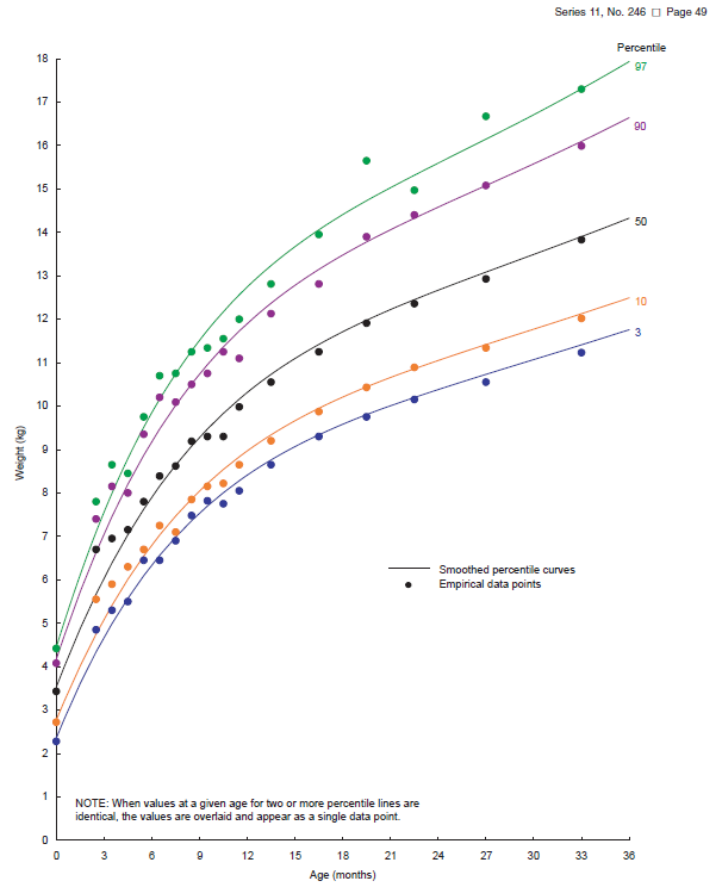


Figure 31. Comparison of smoothed 3rd, 10th, 50th, 90th, 97th percentile curves to empirical data points, birth to 36 months: Boys weight-for-age

## Model

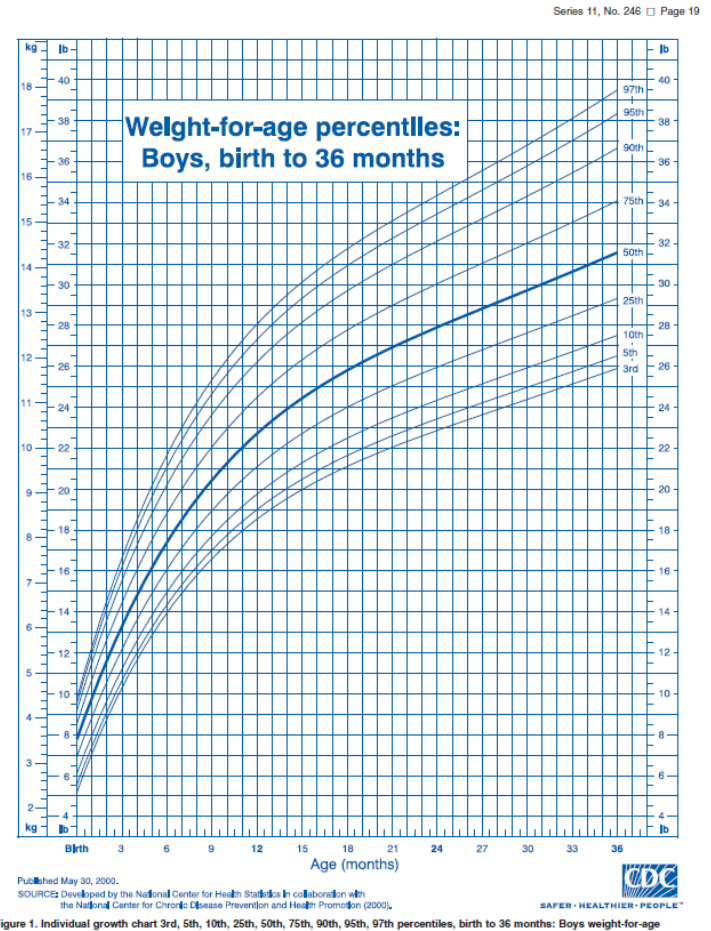
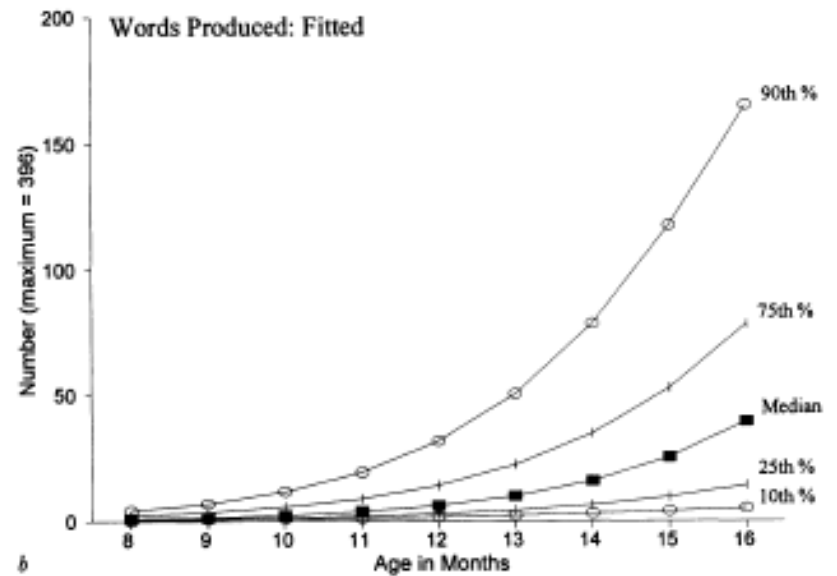
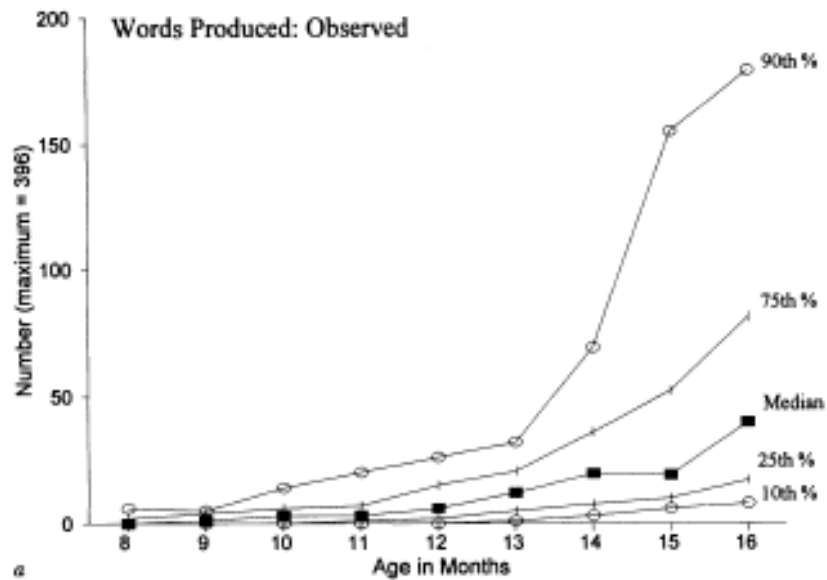


Figure 1. Individual growth chart 3rd, 5th, 10th, 25th, 50th, 75th, 90th, 95th, 97th percentiles, birth to 36 months: Boys weight-for-age

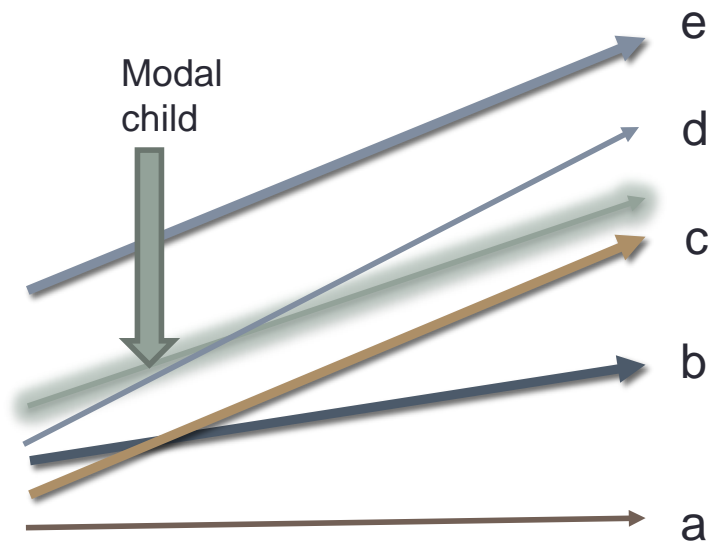
# Growth charts

## Observed data

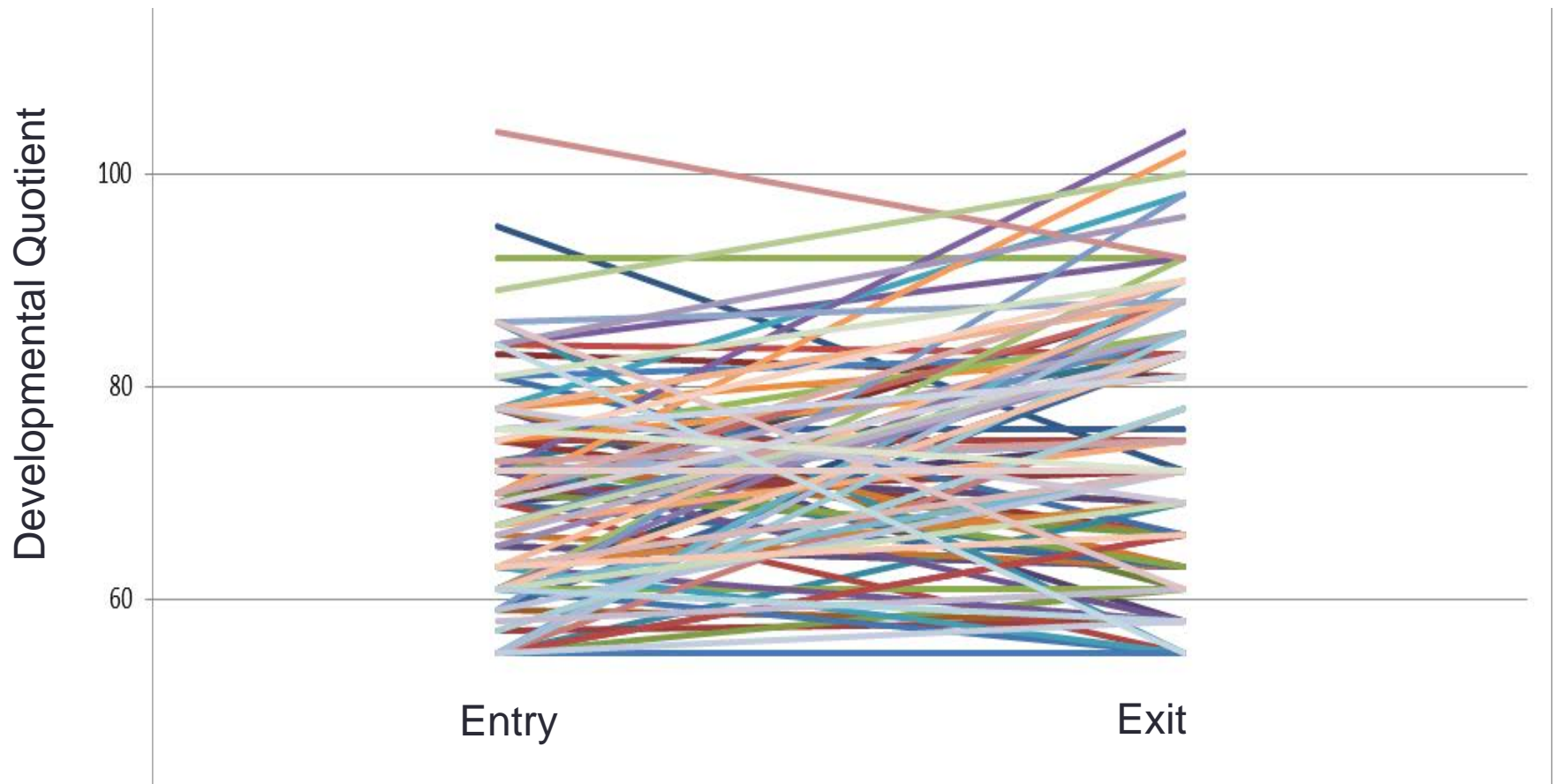




# Developmental trajectories of children in EI, as conceptualized by the Early Childhood Outcomes Center



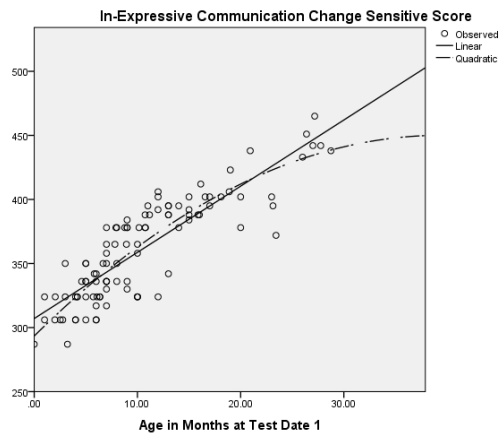
# Developmental trajectories of children in EI, as represented by actual data



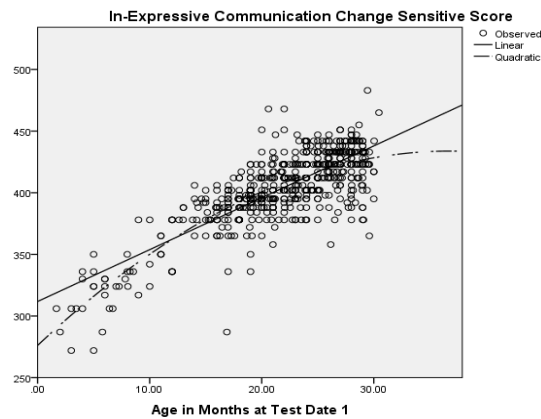
# DO SUBGROUPS OF CHILDREN SHOW DIFFERENTIAL PROGRESS IN EI?

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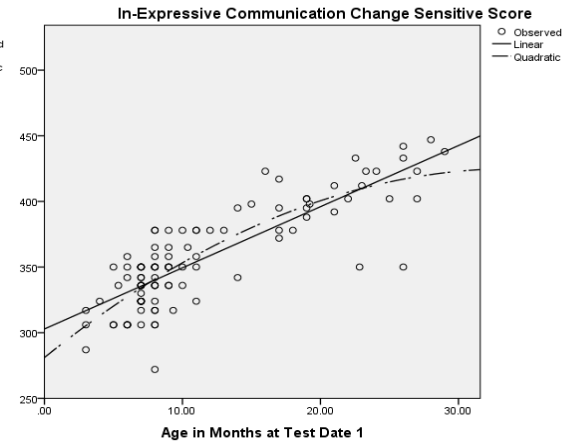
# Expressive communication subdomain score by age on entry into EI



Infants/toddlers  
with motor delay



Infants/toddlers  
with language  
delay

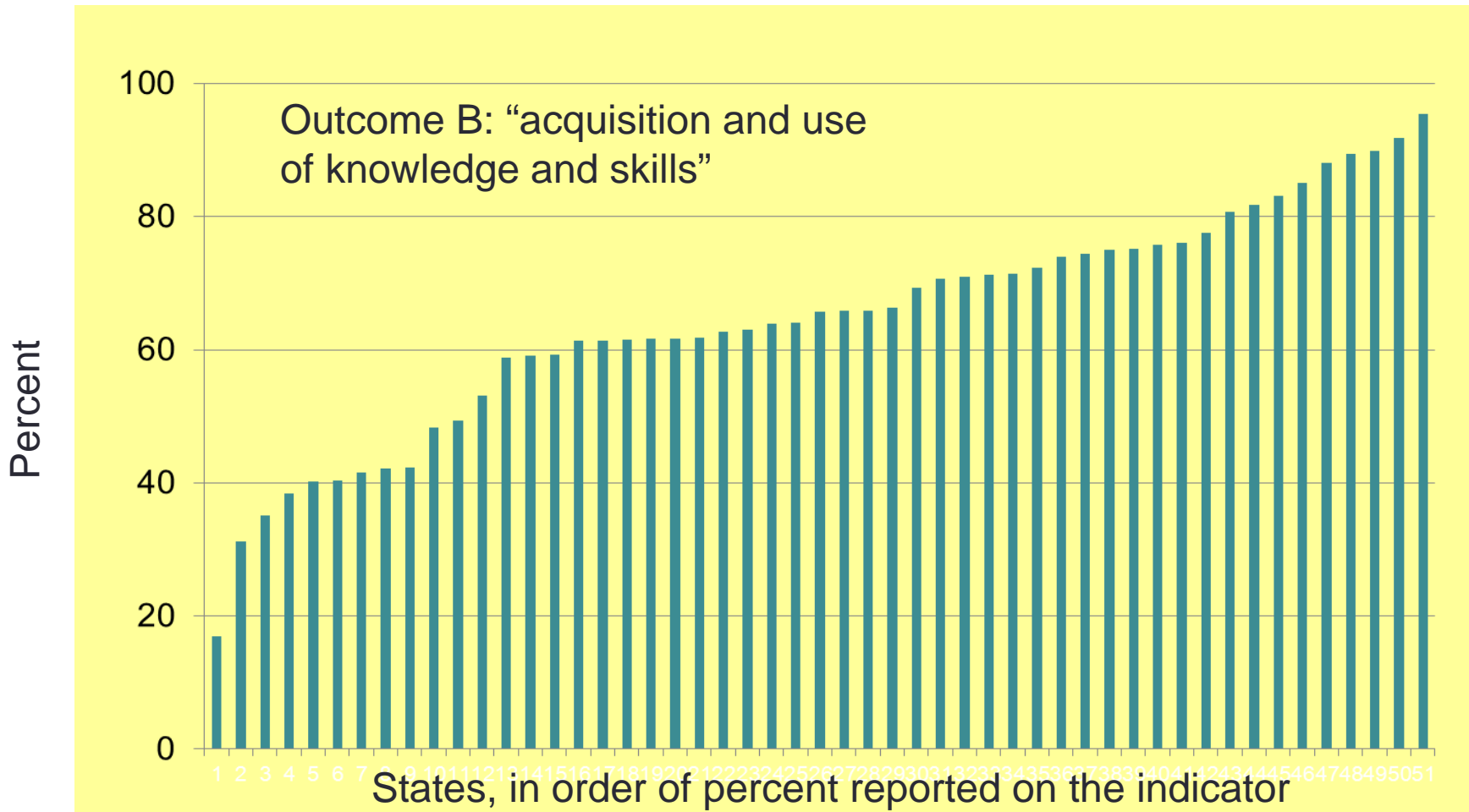


Infants/toddlers  
with extreme  
prematurity

# OUTCOMES OF EI BY STATE

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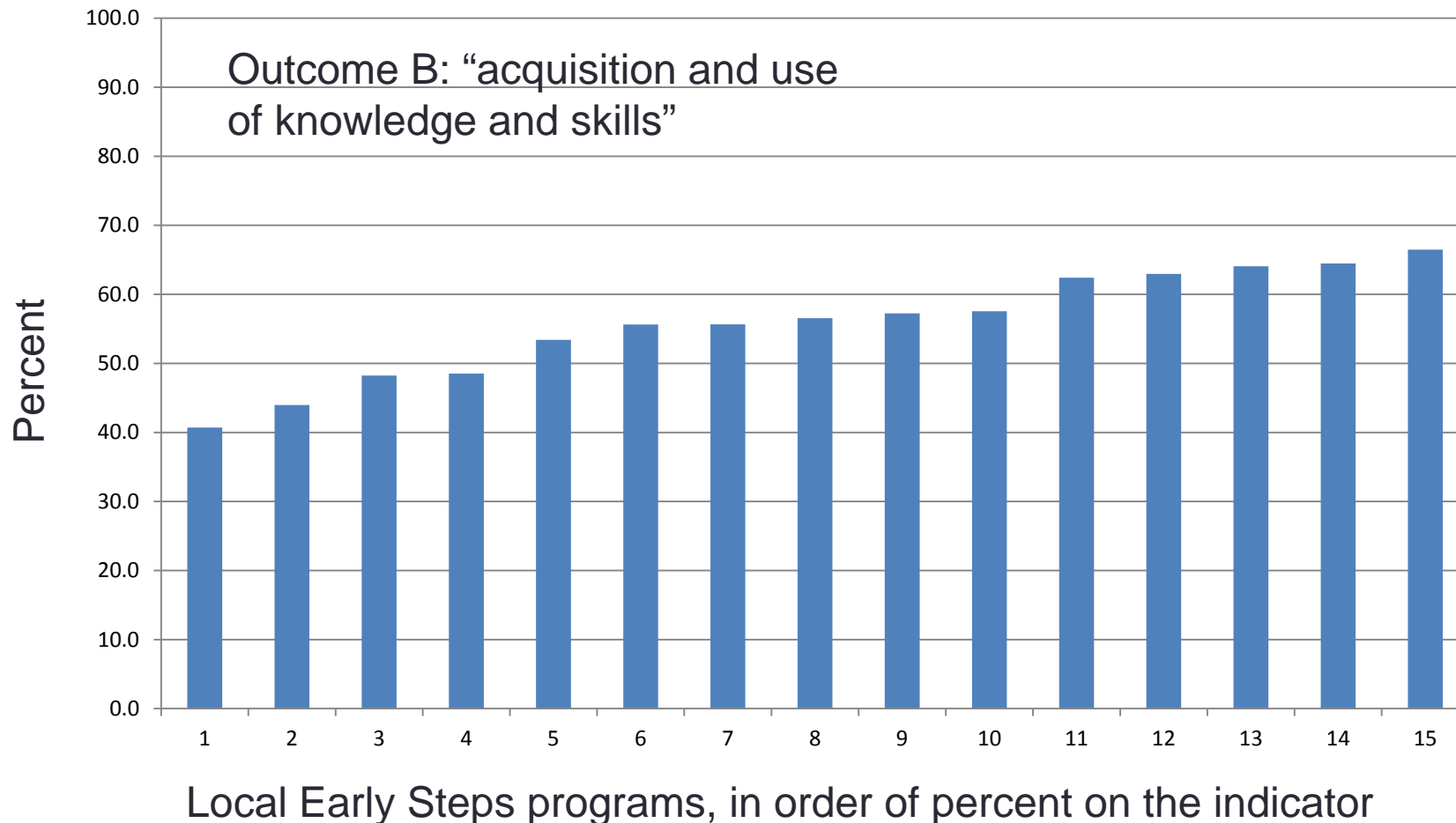
# US States: Percentages of children exiting EI in 2010-11 who “made substantial progress” (ECO Center, 2012)



# OUTCOMES OF EI BY LOCAL PROGRAM WITHIN A STATE

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# Local Early Steps: Percentages of children exiting EI in 2013-14 who “made substantial progress”





CAN PART C PROGRAM  
EFFECTIVENESS BE EVALUATED  
BASED ON CHILDREN'S  
OUTCOMES?

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# Developmental outcomes of children who did or did not receive Part C EI

ECLS-B (n ≈ 8700)				
<i>DID NOT RECEIVE EARLY INTERVENTION</i>				
Cognitive delay at 24 months				
		None	Mild	Moderate/ Severe
Cognitive delay at 9 months				
None	(86.7%)	87.7	6.9	5.5
Mild	(8.5%)	77.7	10.1	12.2
Moderate/severe	(4.7%)	70.6	12.5	16.9
Total sample		86.0	7.4	6.6

FL Part C (n = 565)				
<i>RECEIVED EARLY INTERVENTION</i>				
Cognitive delay at 6-12 mos. <i>M</i> = 8.8 mos.		Cognitive delay at time of EI exit <i>M</i> = 32.8 mos.		
		None	Mild	Moderate/ Severe
None	(43.0%)	36.2	17.7	46.1
Mild	(13.6%)	20.8	16.9	62.3
Moderate/severe	(43.4%)	19.2	12.2	68.6
Total sample		26.7	15.2	58.1

# Factors that may account for variability in reported outcomes

- Variation in the type and severity of children's delays
- Variation in the age at which children enter EI
- Variation in the types and intensity of services provided
- Variation in the expected developmental course of specific conditions
- Variation in the demographic characteristics of children and families served
- Variation in the additional supports and services accessed by families
- Variation in qualifications and training of EI service providers
- Measurement reliability and validity

# Variation in age at entry and mean developmental assessment scores of children entering EI, by local program

<b>Entry Variables</b>	<b>N</b>	<b>Minimum</b>	<b>Maximum</b>	<b>Mean</b>	<b>SD</b>
<b>Age in months</b>	<b>15</b>	<b>17.07</b>	<b>21.17</b>	<b>18.61</b>	<b>1.03</b>
<b>Adaptive DQ</b>	<b>15</b>	<b>78.05</b>	<b>85.79</b>	<b>81.36</b>	<b>2.16</b>
<b>Personal-Social DQ</b>	<b>15</b>	<b>82.74</b>	<b>91.45</b>	<b>86.83</b>	<b>2.70</b>
<b>Communication DQ</b>	<b>15</b>	<b>63.61</b>	<b>74.39</b>	<b>69.49</b>	<b>2.61</b>
<b>Motor DQ</b>	<b>15</b>	<b>82.89</b>	<b>94.15</b>	<b>88.94</b>	<b>3.30</b>
<b>Cognitive DQ</b>	<b>15</b>	<b>73.98</b>	<b>82.64</b>	<b>79.47</b>	<b>2.57</b>

# Intensity of Part C EI services

- Limited data in the public domain
- Variation related to which data are analyzed: services *authorized* (e.g., IFSP documentation) vs. services *provided* (e.g., billing records)
- Variation related to whether *service coordination* is included along with direct services (e.g., speech/language therapy, physical therapy, occupational therapy, special instruction, developmental monitoring)
- Variation in intensity metrics (e.g., mean/median hours per week, mean/median hours per month)
  - For purposes of the following data summary, 1 month = 4.3 weeks

Reference	Sample	Group or subgroup	Mean hours per month	Mean hours per week
Shonkoff et al., 1992 (EICS)	MA/NH, N = 190	<b>Total sample</b>	<b>6.9</b>	<b>1.6</b>
Warfield, 1994 (EICS)	MA, N = 157	Motor impairment, mild cognitive delay, entered EI < 12 months	4.9	1.1
		Motor impairment, mild cognitive delay, entered EI < 12 months	7.8	1.8
		Developmental delay, mild cognitive delay, entered EI < 12 months	6.4	1.5
		Developmental delay, mild cognitive delay, entered EI > 12 months	9.2	2.1
Conn-Powers & Dixon, 2005	IN, N=2480	Children with a delay of 20% in 1 area	1.7	0.4
		Children with a delay of 15% in 2 or more areas	1.7	0.4
		Children with a diagnosed physical/mental condition	1.3	0.3
Hebbeler et al. 2007 (NEILS)	US, N=3338 (20 states)	<b>Total sample</b>	<b>11.2</b>	<b>2.6</b>
Hallam et al., 2009	KY, N=1605	<b>Total sample</b>	<b>11.1</b>	<b>2.6</b>
Hebbeler et al., 2010	TX, N=135 from three geographical regions of the state	Developmental delay	2.5	0.6
		Medical diagnosis	2.2	0.5
		Delay – motor only	2.0	0.5
		Delay – speech only	2.3	0.5
		Delay - global	2.8	0.7
		Entered EI age 0-1	2.0	0.5
		Entered EI age 1-2	2.4	0.6
		Entered EI age 2-3	2.6	0.6
Elbaum et al., in progress	FL, N=1363 children who exited EI 2009-10 to 2012-13	<b>Total sample</b>	<b>5.53</b>	<b>1.3</b>
		EC – Extreme Prematurity (<1200g)	3.56	0.8
		EC – Genetic/Metabolic	8.55	2.0
		EC- Hearing Impairment	4.21	1.0
		DD – Speech	4.74	1.1
		DD – Adaptive	7.13	1.7
		Autism Concern	7.46	1.7

HOW CAN WE MEET THE NEEDS OF  
INFANTS AND TODDLERS WITH  
DEVELOPMENTAL DELAYS AND  
THEIR FAMILIES?

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# Some immediate challenges

- Under-identification of infants and toddlers with or at risk for developmental delays
- Relatively low intensity of Part C EI services
- Questionable utility of publicly reported accountability data
- *Not to mention*
  - Availability of services and supports for children with concerns who do not meet the eligibility criteria for Part C EI
  - The high intensity of evidence-based interventions for the growing number of children identified as having an autism spectrum disorder
  - Family challenges in navigating programs offered through different agencies using different eligibility criteria, assessments, service models, and funding sources





“My question is: Are we making an impact?”

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# Thank you

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