



**UCEDD Resource Center**  
A project of AUCD, in partnership with AIDD, to strengthen and support the network of UCEDDs

# How Persistent are Developmental Delays in Young Children in the US?



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES  
*RESEARCH, EDUCATION, SERVICE*

**Early Intervention/Early Childhood Special Interest Group  
(EIEC SIG)  
Webinar Series  
August 27, 2013**

- Introductions
- Presentation
- Q & A after presentation
  - You can ask a question by pressing the \* then # key to request the floor. Questions will be answered in the order they are received.
  - You can also submit any questions throughout the webinar via the ‘Chat’ box below the slides.
  - The moderator will read the questions after the presentations.
- Survey
  - Please complete our short survey to give us feedback for the next webinar!



**Beth M. McManus, PT, MPH, ScD,  
Assistant Professor, Colorado School of Public Health,  
University of Colorado Children's Outcomes Research  
Group, Children's Hospital Colorado**



**Steven Rosenberg, Ph.D.,  
Associate Professor of Psychiatry at the University of  
Colorado Denver**



**Cordelia Robinson Rosenberg, PhD, RN  
Professor Pediatrics and Psychiatry  
Director, JFK Partners**

# Changes in severity of developmental delays in two longitudinal samples of infants and toddlers

Beth M. McManus, PT, MPH, ScD  
University of Colorado

Steven Rosenberg, PhD  
Cordelia Robinson, RN, PhD  
University of Colorado School of Medicine





# Background

- **The prevalence of developmental delays depends on how delay is defined and measured.**
  - **3.5% have a functional developmental delay** (Simpson et al, 2003)
  - **4% have parent-reported developmental delay** (2003 NSCH)
  - **13% have an objectively measured developmental delay** (Rosenberg et al, 2008)



# Background

- **Previous research using measures of infant development and developmental screeners have found:**
  - Early delays may not predict later development
  - Delays in very young children are not well understood
- **What are the implications for universal developmental screening and referral to early intervention programs?**



# What's not known

- **How persistent are developmental delays in infants & toddlers?**
- **Why is this important to know?**
  - We need to know how long delays last in order to be able to plan for our EI systems
  - Some delays may improve without services
  - How do we best provide anticipatory guidance for families?
  - How do we build optimal school readiness programs?

# Study Questions

- **Are objectively measured delays in infants dynamic?**
  - What % of delays detected in infancy improve, worsen, persist?
- **Controlling for infant and family characteristics, does developmental status at 9-months predict developmental status at 24-months?**



# **METHODS**

# Study Sample #1

- **Early Childhood Longitudinal Study, Birth Cohort (ECLS-B)**
  - Nationally representative sample of infants (n~10,700) born in 2001
  - Evaluated at 9, 24, 48, & 60 months
  - Results based upon ~8,880 with complete data at 9 and 24 months

# Study Sample #2

- **Nurse Family Partnership (NFP)**
  - Sample of socially disadvantaged, first-born infants from 32 states participating in NFP 2008-2012
  - Followed-up at 4, 10, 14, 20 & 24 months
  - Results based upon 3,783 with complete data at 10 and 24 months



# Outcome Measures

- **Developmental Function**

- Measured using the Bayley Short Form Research Edition (BSF-R) in the ECLS-B

- Motor and Cognitive Function subscales

- Measured with Ages and Stages Questionnaire in NFP

- Motor, cognitive, communication, and social skills

# Outcome Measures

## 1. Developmental Delay at 24 months

- None (within 1 SD of mean)
- Mild ( $\geq 1$  and  $< 1.5$  SD below mean)  
[for ECLS-B only]
- Moderate / Severe ( $\geq 1.5$  SD below the mean)

## **2. *Change* in Developmental Delay over time**

–Improving, worsening, or persisting

- **Covariates:** child's sex, race and ethnicity, maternal education, and SES quintile / family income

# Analytic Approach

- Descriptive statistics, prevalence rates of *any* type of delay and *change* in developmental status
- Estimate the odds of having a delay (or more severe delay) at 24-months based upon earlier developmental status, controlling for family characteristics

# RESULTS



# Characteristics of Samples

	Weighted % ECLS-B (n~8,800)	% NFP (n=3,783)
Child's Race and Ethnicity		
white, non-Hispanic	60.5	44.9
black, non-Hispanic	15.3	26.2
Hispanic	18.9	21.0
Other	5.4	8.0
Maternal Education		
Less than high school	13.5	20.9
HS or equivalent	29.1	32.4
Some College	25.9	46.7
College degree	31.5	
Household Income		
Less than \$6,000		24.0
Between \$6,001 - \$12,000		21.3
Between \$12,001 - \$20,000		24.7
Between \$20,001 - \$30,000		16.9
Greater than \$30,001		13.1

# Proportion of children in NFP with delays?

- At 9 months, 18.3% of NFP infants had a delay
- At 24 months, 12.3% of NFP infants had a delay

# Proportion of children in ECLS-B with motor delays

- At **9 months**, **16.1%** had a **motor** delay
  - 9.8% with mild and 6.3% with moderate / severe delay
- At **24 months**, **14.8%** had a **motor** delay
  - 7.2% with mild and 7.6% with moderate / severe delay

# Proportion of children in ECLS-B with cognitive delays

- At **9 months**, **13 %** had a **cognitive** delay
  - 8.5% with mild and 4.7% with moderate delay
- At **24 months**, **14%** had a **cognitive** delay
  - 7.4% with mild and 6.6% with moderate / severe

# Whose Delays Persisted?

- Of the NFP infants with a delay at 9 months,
  - 30.5 % also had a delay at 24 months



# Whose Delays Persisted?

- Of the ECLS-B infants with a cognitive delay at 9 months,
  - 12.7% also had a delay at 24 months (10% with mild and 16.9% with moderate / severe)
- Of the ECLS-B infants with a motor delay at 9 months,
  - 12.9% also had a delay at 24 months (10.3% with mild and 17.3% with moderate / severe)



# Whose Cognitive Delays Improved?

- Of the ECLS-B infants with a **cognitive** delay at 9 months,
  - **61.5%** had less of a delay at 24 months:
    - **12%** improving from moderate / severe to mild
    - **70.6%** improving from moderate / severe to none
    - **77.7%** improving from mild to none

# Whose Motor Delays Improved?

- Of the **ECLS-B** infants with a **motor** delay at 9 months,
  - **66.3%** had less of a delay at 24 months:
    - **8.7%** improving from moderate / severe to mild
    - **74.1%** improving from moderate / severe to none
    - **81.0%** improving from mild to none





# Whose Cognitive Functioning Worsened?

- Of *all* ECLS-B infants at 9 months,
  - 11.4% had worse cognitive function at 24 months:
    - 6.9% moving from no delay to a mild delay
    - 12.2% moving from mild delay to moderate / severe delay
    - 5% moving from no delay to a moderate / severe delay



# Whose Motor Functioning Worsened?

- Of *all* ECLS-B infants at 9 months,
  - 12.1% had worse motor function at 24 months:
    - 6.7% moving from no delay to a mild delay
    - 8.7% moving from mild delay to moderate / severe delay
    - 6.7% moving from no delay to a moderate / severe delay

# Adjusted\*\* Odds of Delay at 24m in NFP sample (n=3,783)

	Adjusted
<b>Delay 10 Months</b>	
None (within 1.5 SD of the mean)	Reference
Yes ( $\leq 1.5$ SD below the mean)	<b>5.1 (4.1 6.2)</b>
<b>Child's Race and Ethnicity</b>	
White, non-Hispanic	Reference
Black, non-Hispanic	<b>1.4 (1.1, 1.8)</b>
Hispanic	<b>1.4 (1.0, 1.8)</b>
Other	1.1 (0.7, 1.6)
<b>Household Income</b>	
Less than \$6,000	<b>1.4 (1.0, 2.1)</b>
Between \$6,001 - \$12,000	<b>1.5 (1.0, 2.1)</b>
Between \$12,001 - \$20,000	1.1 (0.7, 1.5)
Between \$20,001 - \$30,000	0.9 (0.6, 1.4)
Greater than \$30,001	Reference

\*\*Adjusted for maternal education (ns) and child's sex (ns)

## Adjusted Cumulative Odds of Moderate / Severe (Versus “Less Severe”) Delay – ECLS-B

	Cognitive	Motor
<b>Delay 9 Months</b>		
None ( $\geq 1$ SD below the mean)	Reference	Reference
Mild (1.0-1.5 SD below the mean)	<b>2.4 (1.8, 3.2)</b>	<b>1.4 (1.0, 1.8)</b>
Moderate / Severe ( $\leq 1.5$ SD below the mean)	<b>3.3 (2.6, 4.3)</b>	<b>2.6 (2.0, 3.4)</b>
<b>Child’s Race and Ethnicity</b>		
White, non-Hispanic	Reference	Reference
Black, non-Hispanic	<b>1.9 (1.5, 2.3)</b>	<b>0.7 (0.6, 0.9)</b>
Hispanic	<b>2.2 (1.6, 3.1)</b>	1.1 (0.8, 1.5)
Other	1.4 (0.9, 2.0)	0.9 (0.7, 1.3)
<b>Socioeconomic quintile</b>		
First	<b>1.7 (1.1, 2.8)</b>	1.1 (0.7, 1.8)
Second	<b>2.0 (1.3, 3.2)</b>	1.1 (0.7, 1.7)
Third	<b>1.5 (1.0, 2.2)</b>	1.4 (0.9, 2.0)
Fourth	1.1 (0.7, 1.6)	1.0 (0.7, 1.4)
Fifth	Reference	Reference

# **CONCLUSIONS AND IMPLICATIONS**

- **Developmental delays in infants and toddlers are complex and dynamic**
- **The majority of delays will resolve by 24-months, but about 1 in 3 infants will have persistent or late-emerging delays**
- **Patterns of developmental delays are not uniform across racial and ethnic groups**

# Conclusions

## Limitations

- Only two domains measured in ECLS-B
- Only considered two timepoints
- Properties of the BSID & ASQ have been criticized

## Strengths

- Nationally representative sample
- Children did not receive EI for delays
- Accounted for the complex sampling scheme in ECLS-B

# Policy & Programmatic Implications

- **Ongoing, systematic developmental surveillance** is critical to monitor persistent and later-emerging developmental delays, particularly among vulnerable populations.
- Current procedures **may not identify children who will eventually develop delays that require EI services**



# Policy & Programmatic Implications

- Current strategies for identifying delays may make many children candidates for EI **who will catch up without services.**
- Understanding the dynamic nature of delay has important implications for our ability to determine the **optimal timing, intensity, and duration of EI services**

# Acknowledgements

- This study was supported by grants from
  - Maternal and Child Health Research Program (R40 MC 05473),
  - University Center of Excellence in Developmental Disabilities Education, Research and Service (UCEDD), U.S. Department of Health and Human Services, Administration on Developmental Disabilities (90DD0632), and the Colorado Intellectual and Developmental Disabilities Research Center (IDDRC), University of Colorado Denver.
- David Olds, PhD and Nurse Family Partnership Program Office
- No conflicts of interest to disclose.

**Thank You!!**

# Prevalence of Delays at 10- & 24- Months: NFP

Delay at 10 months	Level of Delay at 24 months		
	None	Yes	Total %
None	91.8	8.2	<b>81.7</b>
Yes	69.5	30.5	<b>18.3</b>
<b>Total %</b>	<b>87.7</b>	<b>12.3</b>	

Overall, among all children.....

- About 70% of delays will resolve by 24 months
- About 8% will have late-emerging delays

# Prevalence of Delays at 9- & 24- Months: ECLS-B

Level of Cognitive Delay at 9 months	Level of Cognitive Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	87.7	6.9	5.5	<b>86.7</b>
Mild	77.7	10.1	12.2	<b>8.5</b>
Moderate / Severe	70.6	12.5	16.9	<b>4.7</b>
<b>Total %</b>	<b>86.0</b>	<b>7.4</b>	<b>6.6</b>	
Level of Motor Delay at 9 months	Level of Motor Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	86.6	6.7	6.7	<b>83.9</b>
Mild	81.0	10.3	8.7	<b>9.8</b>
Moderate / Severe	74.1	8.7	17.3	<b>6.3</b>
<b>Total %</b>	<b>85.3</b>	<b>7.2</b>	<b>7.6</b>	

# Whose Delays Persisted?

Level of Cognitive Delay at 9 months	Level of Cognitive Delay at 24 months			
	None	Mild	Moderate / Severe	Total % <sup>b</sup>
None	87.7	6.9	5.5	86.7
Mild	77.7	<b>10.1</b>	12.2	8.5
Moderate / Severe	70.6	12.5	<b>16.9</b>	4.7
Total %	86.0	7.4	6.6	
Level of Motor Delay at 9 months	Level of Motor Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	86.6	6.7	6.7	83.9
Mild	81.0	<b>10.3</b>	8.7	9.8
Moderate / Severe	74.1	8.7	<b>17.3</b>	6.3
Total %	85.3	7.2	7.6	

# Whose Delays Persisted?

Level of Cognitive Delay at 9 months	Level of Cognitive Delay at 24 months			
	None	Mild	Moderate / Severe	Total % <sup>b</sup>
None	87.7	6.9	5.5	86.7
Mild	77.7	<b>10.1</b>	12.2	8.5
Moderate / Severe	70.6	12.5	<b>16.9</b>	4.7
<b>Total %</b>	86.0	7.4	6.6	
Level of Motor Delay at 9 months	Level of Motor Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	86.6	6.7	6.7	83.9
Mild	81.0	<b>10.3</b>	8.7	9.8
Moderate / Severe	74.1	8.7	<b>17.3</b>	6.3
<b>Total %</b>	85.3	7.2	7.6	

Of those with a delay at *either* timepoint, **7%** and **32%** will have persistent delays in cognitive and motor skills, respectively.

# Whose Delays Improved?

Level of Cognitive Delay at 9 months	Level of Cognitive Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	87.7	6.9	5.5	86.7
Mild	<b>77.7</b>	10.1	12.2	8.5
Moderate / Severe	<b>70.6</b>	<b>12.5</b>	16.9	4.7
Total % <sup>c</sup>	86.0	7.4	6.6	
Level of Motor Delay at 9 months	Level of Motor Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	86.6	6.7	6.7	83.9
Mild	<b>81.0</b>	10.3	8.7	9.8
Moderate / Severe	<b>74.1</b>	<b>8.7</b>	17.3	6.3
Total %	85.3	7.2	7.6	

Of those with a delay at 9-months, **50%** and **17%** will show improvement in cognitive and motor skills, respectively.



# Whose Delays Became More Substantial?

Level of Cognitive Delay at 9 months	Level of Cognitive Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	87.7	<b>6.9</b>	5.5	86.7
Mild	77.7	10.1	<b>12.2</b>	8.5
Moderate / Severe	70.6	12.5	16.9	4.7
Total %	86.0	7.4	6.6	
Level of Motor Delay at 9 months	Level of Motor Delay at 24 months			
	None	Mild	Moderate / Severe	Total %
None	86.6	<b>6.7</b>	6.7	83.9
Mild	81.0	10.3	<b>8.7</b>	9.8
Moderate / Severe	74.1	8.7	17.3	6.3
Total %	85.3	7.2	7.6	

Of those with a delay at *either* timepoint, **44%** and **50%** will have worsening delay in cognitive and motor skills, respectively.

# What proportion had a delay?

- At 10 months, **18.3%** of NFP infants had a delay
- Of the ECLS-B infants at 9 months,
  - **13.2 %** had a **cognitive** delay (8.5% with mild and 4.7% with moderate delay)
  - **17.1%** had a **motor** delay (9.8% with mild and 6.3% with moderate / severe delay )

- How to Ask a Question
  - You can ask a question by pressing the \* then # key to request the floor. Questions will be answered in the order they are received.
  - Type your questions into the ‘Chat’ box below the slides and the moderator will read the questions.

## Visit the Websites

- AUCD Website: <http://www.aucd.org>
- EIEC SIG Website: <http://www.aucd.org/eiec>

## Questions about the SIG?

- SIG Co-Chairs
  - Mary Beth Bruder: [bruder@nso1.uch.edu](mailto:bruder@nso1.uch.edu)
  - Corry Robinson: [Cordelia.Rosenberg@ucdenver.edu](mailto:Cordelia.Rosenberg@ucdenver.edu)

## Questions about the Webinar?

- Anna Costalas: [acostas@aucd.org](mailto:acostas@aucd.org)

***Please take a few minutes to complete our survey!***