EARLY INTERVENTION UNDER I.D.E.A.

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

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UNIVERSITY OF MIAMI
BACKGROUND
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?
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.

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 <=-1.5 SD) was approximately 13%.
What percent of children have a developmental delay?
## Children served in EI: U.S. & Florida

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Florida (%) 2011</th>
<th>Florida (%) 2012</th>
<th>Florida (%) 2013</th>
<th>U.S. (%) 2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Birth to 1</td>
<td>0.71</td>
<td>0.71</td>
<td>0.75</td>
<td>1.12</td>
</tr>
<tr>
<td>1 to 2</td>
<td>1.71</td>
<td>1.69</td>
<td>1.79</td>
<td>2.70</td>
</tr>
<tr>
<td>2 to 3</td>
<td>3.26</td>
<td>3.26</td>
<td>3.58</td>
<td>4.71</td>
</tr>
<tr>
<td>Birth to 3</td>
<td><strong>1.89</strong></td>
<td><strong>1.89</strong></td>
<td><strong>2.04</strong></td>
<td><strong>2.85</strong></td>
</tr>
<tr>
<td>3 through 5</td>
<td>5.68</td>
<td>5.71</td>
<td>5.76</td>
<td>6.16</td>
</tr>
</tbody>
</table>
## Children served in EI: U.S. & Florida

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

<table>
<thead>
<tr>
<th>ITCA Categorization of States by Eligibility Criteria</th>
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<tbody>
<tr>
<td>BROAD</td>
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<td>-------</td>
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<tr>
<td>2002</td>
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<tr>
<td>2014</td>
</tr>
</tbody>
</table>
% 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”
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) \textit{with office staff assistance}
  - Developmental Screening \textit{without office staff assistance}
  - Surveillance only

<table>
<thead>
<tr>
<th></th>
<th>Developmental Screening \textit{with office staff assistance}</th>
<th>Developmental Screening \textit{without office staff assistance}</th>
<th>Surveillance</th>
</tr>
</thead>
<tbody>
<tr>
<td>% identified with delays</td>
<td>23.0</td>
<td>26.8</td>
<td>13.0</td>
</tr>
<tr>
<td>% referred to EI</td>
<td>19.9</td>
<td>17.5</td>
<td>10.2</td>
</tr>
<tr>
<td>% determined eligible for EI</td>
<td>7.0</td>
<td>5.3</td>
<td>3.0</td>
</tr>
</tbody>
</table>
But screening is not sufficient to ensure access

- Screening
  - Referral
    - Intake
      - Evaluation
        - Eligibility determination
          - IFSP development
            - Services
Of $N = 1034$ children screened:

- Suspected delay: 202 (20%)
- Referred to EI: 102 (10%)
- Intake: 63 (6%)
- Evaluated: 42 (4%)
- Eligible: 31 (3%)
- Services: 24 (2%)

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
  - Initial IFSP Developed: 12,387
  - Services Started: 11,183
  - Exited at Age 3: 8,546
  - Exited to Part B: 5,697
Florida’s 2008 birth cohort

Connecticut
- Referred to Part C: 19.1%
- Evaluated for Eligibility: 17.9%
- Eligible for Part C EI: 10.9%
- Initial IFSP Developed: 10.4%
- Services Started: 10.1%
-Exited at Age 3: 6.6%
-Exited to Part B: 4.7%

Mississippi
- Referred to Part C: 8.3%
- Evaluated for Eligibility: 5.8%
- Eligible for Part C EI: 5.0%
- Initial IFSP Developed: 5.0%
- Services Started: 4.8%
-Exited at Age 3: 4.3%
-Exited to Part B: 1.8%
EVALUATING OUTCOMES OF PART C EI

*Children’s progress between entry and exit
*Developmental functioning on exit (usually at age 3)
EXPECTED PROGRESS

- For typically developing children
- For children with specific conditions or delays
Weight-for-age percentiles: Boys, birth to 36 months
Growth charts

Observed data

Model

Weight-for-age percentiles:
Boys, birth to 36 months

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

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

NOTE: When values at a given age for two or more percentile lines are identical, the values are overlaid and appear as a single data point.
Growth charts

Observed data

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

Outcome B: “acquisition and use of knowledge and skills”
CAN PART C PROGRAM EFFECTIVENESS BE EVALUATED BASED ON CHILDREN’S OUTCOMES?
Developmental outcomes of children who did or did not receive Part C EI

<table>
<thead>
<tr>
<th>ECLS-B (n ≈ 8700)</th>
<th>DID NOT RECEIVE EARLY INTERVENTION</th>
<th>Cognitive delay at 24 months</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
<td>Mild</td>
</tr>
<tr>
<td>Cognitive delay at 9 months</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>(86.7%)</td>
<td>87.7</td>
</tr>
<tr>
<td>Mild</td>
<td>(8.5%)</td>
<td>77.7</td>
</tr>
<tr>
<td>Moderate/severe</td>
<td>(4.7%)</td>
<td>70.6</td>
</tr>
<tr>
<td>Total sample</td>
<td></td>
<td>86.0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FL Part C (n = 565)</th>
<th>RECEIVED EARLY INTERVENTION</th>
<th>Cognitive delay at 6-12 mos. $M = 8.8$ mos.</th>
<th>Cognitive delay at time of EI exit $M = 32.8$ mos.</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>None</td>
<td>Mild</td>
<td>Moderate/Severe</td>
</tr>
<tr>
<td></td>
<td>(43.0%)</td>
<td>36.2</td>
<td>17.7</td>
</tr>
<tr>
<td></td>
<td>(13.6%)</td>
<td>20.8</td>
<td>16.9</td>
</tr>
<tr>
<td></td>
<td>(43.4%)</td>
<td>19.2</td>
<td>12.2</td>
</tr>
<tr>
<td>Total sample</td>
<td></td>
<td>26.7</td>
<td>15.2</td>
</tr>
</tbody>
</table>
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

<table>
<thead>
<tr>
<th>Entry Variables</th>
<th>N</th>
<th>Minimum</th>
<th>Maximum</th>
<th>Mean</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age in months</td>
<td>15</td>
<td>17.07</td>
<td>21.17</td>
<td>18.61</td>
<td>1.03</td>
</tr>
<tr>
<td>Adaptive DQ</td>
<td>15</td>
<td>78.05</td>
<td>85.79</td>
<td>81.36</td>
<td>2.16</td>
</tr>
<tr>
<td>Personal-Social DQ</td>
<td>15</td>
<td>82.74</td>
<td>91.45</td>
<td>86.83</td>
<td>2.70</td>
</tr>
<tr>
<td>Communication DQ</td>
<td>15</td>
<td>63.61</td>
<td>74.39</td>
<td>69.49</td>
<td>2.61</td>
</tr>
<tr>
<td>Motor DQ</td>
<td>15</td>
<td>82.89</td>
<td>94.15</td>
<td>88.94</td>
<td>3.30</td>
</tr>
<tr>
<td>Cognitive DQ</td>
<td>15</td>
<td>73.98</td>
<td>82.64</td>
<td>79.47</td>
<td>2.57</td>
</tr>
</tbody>
</table>
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
<table>
<thead>
<tr>
<th>Reference</th>
<th>Sample</th>
<th>Group or subgroup</th>
<th>Mean hours per month</th>
<th>Mean hours per week</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shonkoff et al., 1992 (EICS)</td>
<td>MA/NH, N = 190</td>
<td>Total sample</td>
<td>6.9</td>
<td>1.6</td>
</tr>
<tr>
<td>Warfield, 1994 (EICS)</td>
<td>MA, N = 157</td>
<td>Motor impairment, mild cognitive delay, entered EI &lt; 12 months</td>
<td>4.9</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Motor impairment, mild cognitive delay, entered EI &lt; 12 months</td>
<td>7.8</td>
<td>1.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Developmental delay, mild cognitive delay, entered EI &lt; 12 months</td>
<td>6.4</td>
<td>1.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Developmental delay, mild cognitive delay, entered EI &gt; 12 months</td>
<td>9.2</td>
<td>2.1</td>
</tr>
<tr>
<td>Conn-Powers &amp; Dixon, 2005</td>
<td>IN, N=2480</td>
<td>Children with a delay of 20% in 1 area</td>
<td>1.7</td>
<td>0.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Children with a delay of 15% in 2 or more areas</td>
<td>1.7</td>
<td>0.4</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Children with a diagnosed physical/mental condition</td>
<td>1.3</td>
<td>0.3</td>
</tr>
<tr>
<td>Hebbeler et al., 2007 (NEILS)</td>
<td>US, N=3338 (20 states)</td>
<td>Total sample</td>
<td>11.2</td>
<td>2.6</td>
</tr>
<tr>
<td>Hallam et al., 2009</td>
<td>KY, N=1605</td>
<td>Total sample</td>
<td>11.1</td>
<td>2.6</td>
</tr>
<tr>
<td>Hebbeler et al., 2010</td>
<td>TX, N=135 from three geographical regions of the state</td>
<td>Developmental delay</td>
<td>2.5</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Medical diagnosis</td>
<td>2.2</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delay – motor only</td>
<td>2.0</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delay – speech only</td>
<td>2.3</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Delay - global</td>
<td>2.8</td>
<td>0.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Entered EI age 0-1</td>
<td>2.0</td>
<td>0.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Entered EI age 1-2</td>
<td>2.4</td>
<td>0.6</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Entered EI age 2-3</td>
<td>2.6</td>
<td>0.6</td>
</tr>
<tr>
<td>Elbaum et al., in progress</td>
<td>FL, N=1363 children who exited EI 2009-10 to 2012-13</td>
<td>Total sample</td>
<td>5.53</td>
<td>1.3</td>
</tr>
<tr>
<td></td>
<td></td>
<td>EC – Extreme Prematurity (&lt;1200g)</td>
<td>3.56</td>
<td>0.8</td>
</tr>
<tr>
<td></td>
<td></td>
<td>EC – Genetic/Metabolic</td>
<td>8.55</td>
<td>2.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>EC- Hearing Impairment</td>
<td>4.21</td>
<td>1.0</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DD – Speech</td>
<td>4.74</td>
<td>1.1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>DD – Adaptive</td>
<td>7.13</td>
<td>1.7</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Autism Concern</td>
<td>7.46</td>
<td>1.7</td>
</tr>
</tbody>
</table>
HOW CAN WE MEET THE NEEDS OF INFANTS AND TODDLERS WITH DEVELOPMENTAL DELAYS AND THEIR FAMILIES?
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?”


Thank you

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