THE UNITED STATES REGISTRY FOR INFANTS AND TODDLERS WITH VISUAL IMPAIRMENTS

ICEVI Day
August 22, 2016
Orlando, FL

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The overarching goal of Babies Count is to improve services for young children with severe and uncorrectable visual impairments and their families.

(Hatton, et al., 2013)
Impact of *Babies Count*

1. **Defines the population of infants and toddlers**, thus leading to a clear description of the diversity of children with visual impairments.

2. **Identifies early trends** in etiologies of BVI and demographics of children and families
   - data-driven direction to the field of education for BVI to create or improve programs and responsive service delivery, including personnel preparation programs.

3. **Validates funding requests** for appropriate programming.

4. **Allows for research development** in other professions such as medical and sociological.
History of Babies Count

1995-Originally designed and initiated by Model Registry of Early Childhood Visual Impairment Consortium Group, based on program started at Blind Babies Foundation in San Francisco, funded by Hilton-Perkins Foundation

1996-Field tested through various public and private agencies across the country

1997-Data collection began; USDB was the 1st central data repository, and UNC-Chapel Hill analyzed the data

1999- Became official APH project

2011- APH needed to relinquise the project and Preschool BVI Seminar Consortium plans for transition to new home and sponsor.
History of Babies Count cont…

2013- New Mexico School for the Blind takes on project. Consortium begins revisions to data collection form and transition to new database. New Model Registry of EC/VI taskforce group is created to assist with transition.

2015- New data collection form, instructional manual and procedures is finalized and ready for pilot study before new database is created.

March 1, 2016- Database and website available for data collection.

www.babiescount.org
The Survey

- 37 questions total
  - Section A: Child and Family Information
  - Section B: Medical and Visual Information
  - Section C: EI/VI Service Information
  - Section D: Program Exit Information
- Completed by the vision specialist on the team
- Data Collection is done TWICE; at Entry and Exit
to Specialized Vision Service
  - Sections A, B, & C are done at Entry
  - All sections are done at Exit
1. **2001**- 406 babies in 9 states from 1/98 to 6/99


2. **2007**- 2,155 babies in 29 states from 1/00 to 12/04


3. **2013**- 5,931 babies in 28 states from 1/05 to 4/11

1. What are the most **prevalent visual conditions** in young children with severe, uncorrectable vision?

2. What **characteristics** are commonly associated with the most prevalent visual conditions?

3. What are the average ages at which children are **diagnosed and referred** for specialized VI services?
## Most Prevalent Eye Conditions

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2007</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>CVI</strong></td>
<td>21%</td>
<td>23.6%</td>
<td>24.9%</td>
</tr>
<tr>
<td><strong>ROP</strong></td>
<td>17%</td>
<td>16.2%</td>
<td>11.8%</td>
</tr>
<tr>
<td><strong>ONH</strong></td>
<td>8%</td>
<td>9.7%</td>
<td>11.4%</td>
</tr>
</tbody>
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Cortical Visual Impairment (CVI)
Retinopathy of Prematurity (ROP)
Optic Nerve Hypoplasia (ONH)
Prevalence of additional disabilities

Presence of additional disabilities in the top 3 eye conditions

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<tr>
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<th>2001</th>
<th>2007</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVI</td>
<td>79%</td>
<td>88%</td>
<td>85%</td>
</tr>
<tr>
<td>ROP</td>
<td>45%</td>
<td>44%</td>
<td>66%</td>
</tr>
<tr>
<td>ONH</td>
<td>39%</td>
<td>52%</td>
<td>50%</td>
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</tbody>
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Overall, 65% of all babies with VI have additional disabilities.
Dates between diagnosis and referral

<table>
<thead>
<tr>
<th></th>
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<th>2013</th>
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<tbody>
<tr>
<td>Ave age of dx</td>
<td>5.5 months</td>
<td>4.9 months</td>
</tr>
<tr>
<td>Ave age of referral</td>
<td>10 months</td>
<td>10.5 months</td>
</tr>
<tr>
<td>GAP</td>
<td>4.5 months</td>
<td>5.6 months</td>
</tr>
</tbody>
</table>

That is a long time for babies to wait!
Also, ROP is diagnosed the earliest, yet referred latest
CVI is diagnosed the latest in age
Where are we with *Babies Count*?

- Website with database up and running as of 3/1/2016  
  [www.babiescount.org](http://www.babiescount.org)
- States and agencies have access to their own information.
- Currently, we have 9 states participating and more coming. (KY, IN, CA, UT, IL, CO, WA, MD, and NM)
- Project has training activities (webinars and modules) in process.
- A yearly data analysis of national data will be conducted with the first publication in summer of 2017.
- Contact Linda Lyle at NMSBVI for participation.  
  ([llyle@nmsbvi.k12.nm.us](mailto:llyle@nmsbvi.k12.nm.us))