Expectant Participant Outcomes

- **Introduction** to the national project and its **important contribution** to the field of early intervention for young children with blindness/visual impairments (BVI).

- Familiarization with current **epidemiological and demographic** data collected thus far by the project, including the **current trends** it has uncovered.

- Learn how both private and public agencies can **participate** in the project and **benefit** from its implications on program development (including personnel preparation), program evaluation, and funding opportunities.
Mission of Babies Count

The mission of this project is to establish and implement a national registry of young children aged birth to 36 months of age with visual impairments by working with public and private agencies to collect standardized epidemiological and demographic data regarding children, their visual conditions, and the systems created to support them and their families.
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

- A database that will more clearly define the population of infants and toddlers, thus leading to a clear description of the diversity of children with visual impairments.

- Identifies early trends in etiologies and demographics to give data-driven direction to the field of education for the visually impaired to create or improve programs and responsive service delivery, including personnel preparation programs.

- Validates funding requests for appropriate programming.

- Allows for research development in other professions such as educational, medical, and sociological.
Data Analysis and Publications

2001 - 1\textsuperscript{st} data analysis (1/98 to 6/99) on 406 babies from 9 states

2007 - 2\textsuperscript{nd} data analysis (1/00 to 12/04) on 2,155 babies from 29 states

2013 - 3\textsuperscript{rd} analysis (1/05 to 4/11) on 5,931 babies from 28 states
<table>
<thead>
<tr>
<th>State</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>3</td>
</tr>
<tr>
<td>Arizona</td>
<td>95</td>
</tr>
<tr>
<td>California</td>
<td>86</td>
</tr>
<tr>
<td>Colorado</td>
<td>44</td>
</tr>
<tr>
<td>Iowa</td>
<td>5</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>47</td>
</tr>
<tr>
<td>New Mexico</td>
<td>44</td>
</tr>
<tr>
<td>North Carolina</td>
<td>12</td>
</tr>
<tr>
<td>Utah</td>
<td>70</td>
</tr>
<tr>
<td><strong>Total:</strong></td>
<td><strong>406</strong></td>
</tr>
</tbody>
</table>

Note:

Does not indicate that AZ has more babies with BVI than any other state, nor does this identify ALL the babies with BVI in each state. This represents the surveys completed by dedicated agencies on the babies and families newly referred during a particular point of time.
History of Babies Count

1995- Originally initiated and designed 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 central data repository, and UNC-Chapel Hill analyzed the data

1999- Became official APH project
History of Babies Count cont...

2011- APH relinquished the project because it does not fit within their federal charter, yet they continue to house database. Preschool BVI Seminar Consortium plans for transition to new home and sponsor.

2013- New Mexico School for the Blind steps up. 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.

2014- New data collection form is finalized and ready for new database and procedures to be developed.

Now- New database is under development. Data collection is expected to begin Sept. 2015.
Survey Items:

Section A. Child and Family Information
1. Gender
2. Ethnicity
3. Zip Code
4. DOB
5. Gestational Age at Birth
6. Birth Weight
7. Multiple Birth
8. Bio Mom’s Age at Birth
9. Bio Dad’s Age at Birth
10. Child Lives With:
11. Primary Language
12. Educational Levels of Custodial Mom and Dad
Survey Items:

Section B: Medical and Visual Information
13. Medical information retrieved from:
14. Date of or age at visual diagnosis
15. Primary diagnosis in right eye
16. Additional diagnosis in right eye
17. Primary diagnosis in left eye
18. Additional diagnosis in left eye
19. Etiology of VI
20. If post-natal, is it NAT?
21. Glasses, contacts, prosthesis?
22. Additional medical/health concerns
23. Presence of additional developmental delays
24. Level of functional vision
25. Overall developmental needs
26. Primary learning channel
Survey Items:

Section C: EI/VI Service Information
27. Date of referral for specialized VI service
28. Date of enrollment
29. Referral source
30. Frequency of specialized VI service
31. Type of specialized VI service
32. Location of specialized VI service
33. Other services on IFSP
Survey Items:

Section D: Program Exit Information
35. Date of exit
36. Reason for exit
37. Receiving program
38. Specialized VI services in new program

Basic Procedures:
Completed by the vision specialist on the team
• EI/TVI, TVI, or O&M

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
Target Research Questions

1. What are the most **prevalent visual conditions** in young children?

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 services?

(Hatton, 2001; Hatton, et.al., 2007; Hatton, et.al., 2013)
## Target #1:
3 Most Prevalent Diagnoses

<table>
<thead>
<tr>
<th></th>
<th>2001</th>
<th>2007</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>CVI</td>
<td>21%</td>
<td>23.6%</td>
<td>24.9%</td>
</tr>
<tr>
<td>ROP</td>
<td>17%</td>
<td>16.2%</td>
<td>11.8%</td>
</tr>
<tr>
<td>ONH</td>
<td>8%</td>
<td>9.7%</td>
<td>11.4%</td>
</tr>
</tbody>
</table>

(Hatton, 2001; Hatton, et.al., 2007; Hatton, et.al., 2013)
Cortical Visual Impairment

- Impaired vision due to damage to the brain

  Occipital lobes / Visual Cortex
  AND/OR
  “Higher” visual analysis systems: Dorsal and Ventral streams

- **Trend:** No change
Retinopathy of Prematurity

- Affects immature blood vessels of the retina in premature infants

- **Trend:** Decreasing, but increasing incidence of additional disabilities
Optic Nerve Hypoplasia

- Underdeveloped optic nerves
- With or without additional midline brain malformations involving neurologic and endocrine dysfunction
- Trend: Increasing
The 3 leading causes of BVI in children in US...

- All involve different areas of the visual system
  (brain, retina, and optic nerves)
- Is consistent with other developed countries
  (Canada, England, Australia)
Target #2: Prevalence of additional disabilities

Overall, 65% of all babies with BVI have additional disabilities.

Presence of additional disabilities is increasing in the top 3

<table>
<thead>
<tr>
<th>Year</th>
<th>CVI</th>
<th>ROP</th>
<th>ONH</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>79%</td>
<td>45%</td>
<td>39%</td>
</tr>
<tr>
<td>2007</td>
<td>88%</td>
<td>44%</td>
<td>52%</td>
</tr>
<tr>
<td>2013</td>
<td>85%</td>
<td>66%</td>
<td>50%</td>
</tr>
</tbody>
</table>

(Hatton, 2001; Hatton, et.al., 2007; Hatton, et.al., 2013)
Target #3:
Dates between diagnosis and referral for Vision Services

- Average age of diagnosis is 4.9 mo (2013), 5.5 mo (2007)
- Average age of referral is 10.5 mo (2013), 10.0 mo (2007)
- Consistent lag of 5 months between diagnosis and referral
  (That is a long time for babies to wait!)

- ROP is diagnosed the earliest, yet referred latest
- ONH is being diagnosed sooner
- CVI is diagnosed and referred last.
- VI conditions that have physical manifestations are diagnosed the earliest.

(Hatton, 2001; Hatton, et.al., 2007; Hatton, et.al., 2013)
Why participate in Babies Count?

Collective effort on a national level to gather information about our population which could lead to:

- Identify epidemiological trends in population
- Improve teacher preparation programs
- Increase quality of responsive EI services
- Create overall accountability across the field

When you know better, you do better! - Oprah
What is the **direct benefit** of Babies Count to agencies?

States (designated stakeholder) and individual agencies will have direct and immediate access to their data

- Funding rationale for service delivery program development
- Comparative demographic information and responsive programming
Special Thanks to the Babies Count EC/VI Collaborative Task Force

Gail Calvello- Blind Babies Foundation, California

JC Greeley- Anchor Center for Blind Children, Colorado (retired)

Karen Frank- Maryland School for the Blind

Amy Hyman- Foundation for Blind Children, Arizona

Ann Nielsen- Kansas State School for the Deaf and Blind

Kay Ferrell- University of Northern Colorado

Linda Lawrence- Pediatric Ophthalmologist, Kansas

Burt Boyer- American Printing House for the Blind (retired)

Linda Lyle- New Mexico School for the Blind and Visually Impaired

Andrea Montano- New Mexico School for the Blind and Visually Impaired

DeEtte Snyder- Washington State School for the Blind