Babies Count:
The National Registry for Infants and Toddlers with Visual Impairments

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Expectant Participant Outcomes

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

- 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.

- Exploration of the new Babies Count Survey and implementation of data collection
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.
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

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.

2015- Funding secured through APH Foundation for continuation of project!

Now- New database is under development. Beta test data collection is expected to begin Nov. 2015. Nationwide data collection in Jan 2016!
Let’s dig into the survey...
Basic Procedures:

1. Online submission
2. Completed by the vision specialist on the team
   • EI/TVI, TVI, or O&M
3. Four sections with 37 questions total.
4. Data Collection is done TWICE
   • Entry AND Exit of specialized vision services
   • Sections A, B, & C are done at Entry
   • All sections (A, B, C, & D) are done at Exit
Section A: Child and Family

Information about the child:

1. Gender: Male or Female
2. Ethnicity of child (check all that apply):
   - Caucasian/White
   - African American/Black
   - Native Alaskan/American Indian
   - Asian
   - Hispanic/Latino
   - Pacific Islander
   - Middle Eastern/North African
   - Other OR Unknown
3. Postal zip code of primary residence
4. Date of Birth
5. Gestational age at birth
   - Age in Weeks ______
   - Full Term
   - Unknown
6. Birth weight
   - grams or lbs or unknown.
7. Multiple birth?
Section A: Child and Family

Information about the Parents/Guardian:

8. Biological age of mom at birth
9. Biological age of dad at birth
10. Child currently lives with:
11. Is English the primary language?
12. Level of education of mom and dad
Section B: Medical and Visual Information

13. Medical information retrieved from:
   - Medical records OR
   - Parent report
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:
   - Pre, Peri, OR Post
20. If post-natal, is it NAT?
21. Glasses, contacts, prosthesis?
22. Additional medical/health concerns
23. Presence of additional developmental delays
Section B: Medical and Visual Information

Summary of Child

24. Level of functional vision
   • Normal or near normal vision
   • Low vision
   • Meets the definition of blindness
   • Functions at the definition of blindness

25. Overall developmental needs
   • Typical development
   • Mild to moderate support needs
   • Intensive support needs

26. Primary learning channel
   • Visual
   • Tactual
   • Auditory
Section C: EI/VI Service Information

27. Date of **referral** for specialized VI service

28. Date of **enrollment** to specialize VI service

29. Referral source

30. **WHO** is providing specialized VI service?

31. **WHAT** type of specialized VI service?

32. **WHERE** is specialized VI service provided?

33. Other services on IFSP
Section D: Program Exit Information

Transitional Information:

34. Date of exit from specialized VI services
35. Reason child exited specialized VI service
36. If child exited from program at age 3, indicate type of program child is transitioning to.
37. Will specialized VI services be provided to this child in new setting?

*Completed at exit only
Questions? Clarifications? Comments?
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

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