



THE UNITED STATES REGISTRY FOR INFANTS AND TODDLERS WITH VISUAL IMPAIRMENTS

ICEVI Day
August 22, 2016
Orlando, FL

DeEtte Snyder
Washington State School for the Blind
DeEtte.Snyder@wssb.wa.org

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 relinquish 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

Data Analysis and Publications

1. 2001- 406 babies in 9 states from 1/98 to 6/99

Hatton, D. (2001). Model registry of early childhood visual impairment: First year results. *Journal of Visual Impairment & Blindness*, 95, 418-433.

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

Hatton, D., Schwietz, E., Boyer, B., & Rychwalski, P. (2007). Babies Count: The national registry for children with visual impairments, birth to three years. *Journal of American Association for Pediatric Ophthalmology and Strabismus*, 11, 351-355.

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

Hatton, D., Ivy, S., & Boyer, C. (2013). Severe visual impairments in infants and toddlers in the United States. *Journal of Visual Impairment & Blindness*, 107, 325-336.

Target Research Questions

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

	2001	2007	2013
CVI	21%	23.6%	24.9%
ROP	17%	16.2%	11.8%
ONH	8%	9.7%	11.4%

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

	2001	2007	2013
CVI	79%	88%	85%
ROP	45%	44%	66%
ONH	39%	52%	50%

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

Dates between diagnosis and referral

	2007	2013
Ave age of dx	5.5 months	4.9 months
Ave age of referral	10 months	10.5 months
GAP	4.5 months	5.6 months

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
- 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)