

Call to Action: The Babies Count National Registry of Infants and Toddlers with Visual Impairment

Dorinda Rife, MA, CLVT, COMS;

Dorinda Rife Consulting, LLC;
dorinda@dorindarife.com

You've heard the taglines: Babies count, they matter too! Babies grow up to be fourth graders! The face of blindness is changing! We need more data! What's the hype about? Let's dive into the importance of data on our population in the field of education of young children and students with visual impairment (VI) and in the practice as teachers of children with VI, but more importantly how all of us have a duty to participate.

Babies Count is a national registry and was established almost 25 years ago to address the insufficient data collected on infants and toddlers with (VI). The project's vision is to gather information about children with VI aged 0-36 months, specifically etiology, visual functioning, coexisting conditions, and early intervention (EI) services. The data acquired through Babies Count have the potential to inform personnel preparation, product development, legislation, and funding to support children with VI across their educational lifespans.

A lack of federal consensus regarding epidemiology or demographics of children with VI in the United States has made it difficult for researchers and program administrators to access accurate data about this special population. The Office of Special Education Programs (OSEP) has failed to take the lead in creating a mechanism to adequately count children with VI, who are served through diverse special education programs and services in every state. Several factors contribute to this failure. For example, some states are non-categorical, meaning that they do not always assign the label of “visual impairment” to students who meet the federal definition of blindness or VI. Also, students with the label of multiple disabilities may not always carry a secondary or tertiary label such as VI. In addition, classification language related to children with VI varies across organizations, professional research, and both the education and medical fields. Names of syndromes, diseases, and physical or neurological features that pertain to VI and blindness are applied inconsistently, making data collection and analysis challenging. In an attempt to counteract all these limitations, Babies Count collects information using consistent terminology that the field will be able to analyze and add to over multiple years therefore creating a longitudinal view of the population.

Babies Count was first piloted in 1996 with the first data analysis completed in 1999 by Dr. Deborah Hatton and published in 2001 (Hatton, 2001). The project was managed by the American Printing House for the Blind (APH) from 2000 to 2011, under the direction of Project Leader Burt Boyer. When the federal government informed APH that it could no longer use federal funds to support Babies Count in 2011, the survey languished. Piles of paper surveys lay untouched in file cabinets at APH until a group of motivated early childhood VI specialists, comprised of members of the Early Childhood Visual Impairment Alliance (ECVIA) and led by Linda Lyle from the New Mexico School for the Blind and Visually Impaired (NMSBVI), revitalized the Babies Count project. Starting in 2013, they updated the survey and by 2016 they created an online version of the original with data collection happening through a secure website.

The website, Babiescount.org, is a comprehensive portal that shares information about the history, mission, and vision for the Babies Count project. It includes an inspirational video about the project and a connection to the online survey that serves as the foundation for the database. The site offers the user an opportunity to download the survey as a Word document, but also the ability to complete it electronically with families directly. The survey collects information on individual children ages 0-36 months initially

when the child enters specialized VI services through an Early Intervention (EI) program, then again when the child exits specialized VI services.

Survey information is collected by the educational professional who is providing the specialized EI/VI service (typically a teacher of children with VI) through a combination of parent report and/or records review (if records are available). The Babies Count advisory committee, comprised of members from ECVIA, recommend that a parent interview is always part of data collection. Information is collected in three main areas of inquiry: (a) the child's vision etiology and functioning, related medical information, and areas of existing developmental delay, (b) variables related to the child's family, and (c) variables related to the child's early intervention services.

In 2018, Dr. DeEtte Snyder completed the fourth and most recent analysis of the data from Babies Count in her doctoral dissertation. Some highlights of that research include the shift in visual condition etiology, the high prevalence of co-existing development disabilities and other medical conditions, and the diversity and size Individual Family Service Plan (IFSP) teams. In the three previous analyses of data from Hatton (2001), Hatton, Schwietz, Boyer, & Rychwalski (2007), and Hatton, Ivy, and Boyer (2013), Cortical Visual Impairment (CVI), Retinopathy of Prematurity (ROP), and Optic Nerve Hypoplasia (ONH) were, in that order, the top reported eye

conditions. In Snyder's analysis, ONH replaced ROP as the second most reported condition. This shift documents the potential change in etiology of visual diagnosis leading to VI that is expected to evolve as the ROP prevalence continues to decline. The presence of co-existing medical conditions and developmental disability in a large percentage of young children with visual impairment is also verified through Babies Count data. In a sample size of 588, over 80% of the children were identified as having additional developmental delays. Potentially related to prevalence of co-existing developmental delays, IFSP teams were reported as large, with about half of the sample indicating that teams consisted of 4 or more EI professionals. In addition, 41% of the sample reporting the specialized VI teacher providing EI support on a once a month frequency (Snyder, 2018). This information about the size and make-up of EI teams will help the field understand the complexity of EI services for children with VI, especially when the specialized VI provider is a consultant or coach and not a direct service provider.

As the New Mexico version of the project came to life, Lyle continued to have a bigger—and a truly national—vision for the project by having all 50 states included in data collection and analysis. However, she needed additional resources to market its benefits to organizations that could

facilitate its growth and to develop training around completion of the survey. Hallway conversations over several years turned that dream into a reality when NMSBVI and APH created a Memorandum of Understanding outlining a two-year (2018 to 2020) vision to bring the project back to APH and enhance its national focus.

Currently thirteen states are signed up to collect survey information on children 0-36 months with 5 states included in Snyder's analysis (Snyder, 2018). The current framework follows this line of participation: (a) each state chooses a "state administrator" depending on each state's EI/VI service delivery model, (b) the state administrator registers each EI/VI program in the state as some states may have more than one, (c) the EI/VI program then registers individual EI/VI providers who complete surveys for children on their caseloads with the family's input.

Dorinda Rife and Susan Sullivan, working on behalf of APH, and Linda Lyle, working on behalf of NMSBVI, are partner project co-leaders for Babies Count. With guidance from the project leaders, the advisory committee is focused on widening the number of states submitting data to the Babies Count registry. The advisory committee is also committed to analyzing the collective national data on a regular basis for publication, however each state and individual program also has access to their own

data for the children within their program(s). Individual state and program data is accessible by each administrator and can be used for program decisions at any time.

A bigger, more diverse data pool will strengthen our field's ability to obtain meaningful data that will inform the field for years to come. Barriers to signing on new states have been identified, however. One barrier may be due to individual states with different EI systems, including diverse models of specialized VI services, and it has been difficult to find a "champion" for Babies Count to partner. Also, EI/VI service providers with large caseloads may balk at "one more thing" to do with families. While these issues may pose barriers today, they are not insurmountable. Current users of the registry report that completing the survey during a home visit can enrich the exchange of information between parent and practitioner. It can offer a platform for deeper discussion about the child including their experiences in the early months and years, and help clarify the significance of various factors in the child's life for both practitioner and family member. Also, programs have found this level of information critical for funding requests.

Imagine filling out a survey with a family to learn more about a baby's first years. Sounds pretty easy, doesn't it? Now imagine the impact that

simple act might have on the field of visual impairment and blindness. That impact has a name: Babies Count. How can you get involved with Babies Count? Peruse the website to get a general feel for the project. Then use the site's "Contact Us" feature to become a part of this important movement.

References

- Hatton, D. (2001). Model registry of early childhood visual impairment: First year results. *Journal of Visual Impairment & Blindness, 95*, 418-433.
- 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.
- 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.
- Snyder, D. (2018). Identification of young children with visual impairments including unique characteristic and factors related to responsive services. Published Doctor of Philosophy dissertation, University of Northern Colorado.