

Using Evidence-based Strategies and Technical Assistance to Improve Identification of Infants and Toddlers with Combined Vision and Hearing Loss

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Experiences that occur during the earliest years of life critically impact children's abilities to learn, move, and interact with others. This is especially true for children with severe sensory and multiple disabilities, for whom bonding, communication, incidental learning, social interaction, motor development and mobility are particularly challenging (Malloy et al., 2009). A National Deaf-Blind Technical Assistance Network, comprised of individual and multi-state deaf-blind projects and the [National Center on Deaf-Blindness](#), exists to help families of these children improve early developmental outcomes. However, the expertise and resources available through this network are not often accessed during the first three years of life.

For the past 30 years, the National Center on Deaf-Blindness (NCDB) and its predecessors have conducted an annual count of children birth through 21 years of age with deaf-blindness. Over the five year span (2009-2013) the average number of children identified with combined vision and hearing loss under age three across all states and territories has been 582, which represents 6.2% of the total number. Even more significant is that on average only 76 infants under one year of age have been identified across all states and territories. This represents less than 1% of the total of

the total of children, birth through 21, identified in the National Deaf-Blind Child Count. During this same period, 47 states/territories had one or more years with no children birth-age one identified. Only 7 states identified children birth-age one each year. (Schalock & Bull, 2010, 2011, 2012, 2013, in press).

Increasing awareness about the diversity within this low incidence population is crucial in order to facilitate connections with the foundational services and interventions needed for the greatest success. This can be challenging given that:

- deafblindness can be a misleading term, since residual vision and hearing are usually present;
- families, educators and medical professionals may not recognize the impact of *combined* vision and hearing loss on early learning;
- more than 90% of these children have additional disabilities, including complex medical challenges; and
- due to federal regulation, programs for young children with disabilities are non-categorical.

A multi-pronged approach, undertaken by NCDB, has demonstrated positive results in the early identification and referral of young children who are deaf-blind within states. The approach employs data-based decision making, implementation of evidence-based identification and referral practices, collaboration among state deaf-blind projects, a toolbox of common materials and technical assistance delivered by an experienced Early Identification & Referral (EI&R) Team.

An online [Self-Assessment Guide](#) allows state deafblind projects to analyze state and national data, gather information about systems in their state serving children birth through two years old, and reflect on specific issues that impact identification and referral of infants and toddlers with combined vision and hearing loss. An extensive literature review, combined with strategies from deaf-blind projects with consistently high referral counts, has provided a set of effective practices for use by the national deaf-blind technical assistance (TA) network.

In addition, network members utilize and contribute to an online repository of resources that:

- differentiate between identification (recognition that both vision and hearing loss exist and understanding the impact on early learning) and referral (ensuring families are linked to their state deaf-blind projects and other specialized services);
- link to both an identified issue and a recommended practice;
- target a particular system (Part C programs, Early Hearing Detection and Intervention (EHDI) programs, the medical community and other programs serving children birth through two and their families); and
- provides tips and examples from colleagues who have participated in the self-assessment process and implemented recommended practices.

Currently, nearly 50% of 49 state/multi-state deafblind projects have utilized the self-assessment guide and are beginning to implement one or more of the four key

evidence-based practices recommended by the national center. The nine states participating in a pilot of this process identified 104 of the 344 newly identified infants and toddlers in 2012. Collectively, their birth through two child count has increased from 136 in 2011 to 179 in 2013.

Missouri and Tennessee are two states in which the self-assessment indicated regions within the state where no infants or toddlers were being identified. By narrowing their focus and implementing selected evidence-based practices both states have experienced a steady increase in their birth through two counts. Missouri has seen an increase from 13 to 29 in the past three years and Tennessee's count has increased from 19 to 37.

As this work continues, more state deaf-blind projects are discovering that by using data-based decision making to narrow their focus and identify the early intervention system with the highest potential and feasibility for impact their limited resources will be more effective. Through the implementation of recommended evidence-based practices related to building relationships, developing carefully targeted materials, being clear about the benefits of referral and consistently following-up with referral resources, state deafblind projects are building their capacity to increase the numbers of infants and toddlers with combined vision and hearing loss who are receiving appropriate early intervention services.

References

- Malloy, P., Stremel-Thomas, K., Schalock, M., Davies, S., Purvis, B. & Udell, T., (2009). *Early Identification of infants who are deaf-blind*. Monmouth, OR: National Consortium on Deaf-Blindness, Teaching Research Institute, Western Oregon University.
- Schalock, M.D. and Bull, R. (in press). *The 2013 National Child Count of Children and Youth who are Deaf-Blind*. Monmouth, OR: National Center on Deaf-Blindness, Teaching Research Institute, Western Oregon University
- Schalock, M.D., & Bull, R. (2013). *The 2012 National Child Count of Children and Youth who are Deaf-Blind*. Monmouth, OR: National Consortium on Deaf-Blindness, Teaching Research Institute, Western Oregon University
- Schalock, M.D., & Bull, R. (2012). *The 2011 National Child Count of Children and Youth who are Deaf-Blind*. Monmouth, OR: National Consortium on Deaf-Blindness, Teaching Research Institute, Western Oregon University
- Schalock, M.D., & Bull, R. (2011). *The 2010 National Child Count of Children and Youth who are Deaf-Blind*. Monmouth, OR: National Consortium on Deaf-Blindness, Teaching Research Institute, Western Oregon University
- Schalock, M.D., & Bull, R. (2010). *The 2009 National Child Count of Children and Youth who are Deaf-Blind*. Monmouth, OR: National Consortium on Deaf-Blindness, Teaching Research Institute, Western Oregon University.

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