

# Early Identification and Referral of Infants Who Are Deaf-Blind

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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 physical, communicative, cognitive, social, and emotional developmental domains are deeply intertwined. In recognition of the importance of appropriate early learning experiences for children who are deaf-blind, in 2006 the National Consortium on Deaf-Blindness (NCDB) selected early childhood identification and intervention as one of five focus areas for the formation of partnerships to promote initiatives aligned with federal priorities to meet the most frequently identified needs of children and youth who are deaf-blind and their families and service providers.

In July 2007, an NCDB work group was established to lead activities in the early childhood identification and intervention focus area. The initial tasks of the group were to gather information about current needs and practices and to identify potential state and national entities interested in forming partnerships with NCDB on early childhood initiatives. The following three primary activities were conducted to accomplish these tasks: (a) a survey of state deaf-blind project directors, (b) focus group interviews with state deaf-blind project personnel in eight states, and (c) an extensive literature review. Collectively, the findings from these activities indicate a need for new strategies to improve early identification of infants and young children who are deaf-blind and increase referrals of them to state deaf-blind projects. As a result, the work group narrowed its focus to efforts designed to promote early identification and referral. This report describes the findings that led to this decision and discusses current initiatives undertaken by

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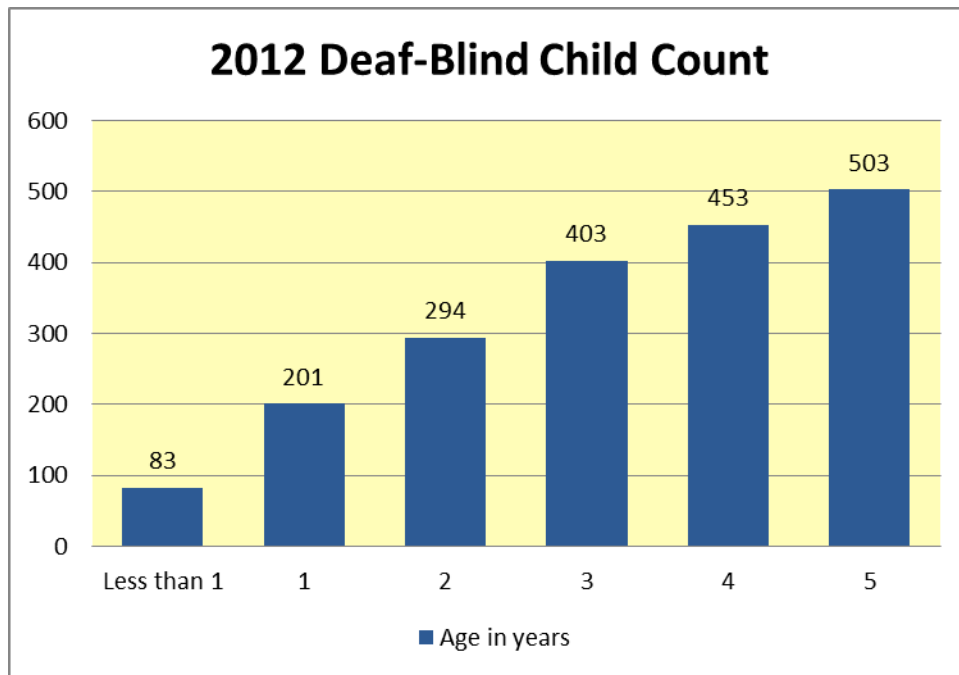
NCDB and state deaf-blind projects to improve early identification of children who are deaf-blind and referral to appropriate services.

## **The Need for Initiatives to Improve Early Identification**

Experts who work with children who have disabilities have long believed that early intervention services improve educational and social outcomes (Guralnick, 1997). The early years of life are important, particularly for communication and language development, because this is the time of life when the brain is at its highest capacity to undergo structural changes in response to external stimulation, a process known as neural plasticity (Cole & Flexer, 2007, p. 2). Although no studies have investigated outcomes associated with early intervention for children who are deaf-blind, numerous studies have shown that infants who receive early identification and intervention for hearing loss in the first few months of life achieve significantly greater language skills than those who are identified later (Apuzzo & Yoshinaga-Itano, 1995; Calderon & Naidu, 2000; Kennedy et al., 2006; Moeller, 2000; Yoshinaga-Itano, Coulter, & Thomson, 2000; Yoshinaga-Itano, Sedey, Coulter, & Mehl, 1998). Additionally, research on the plasticity of the brain related to hearing and visual perception strongly supports the need for early identification and early provision of services (Mitchell & Maslin, 2007; Sharma, Gilley, Dorman, & Baldwin, 2007).

Among professionals who work in the field of deaf-blindness, there is a strong consensus that early intervention is crucial (Murdoch, 2004), but findings from the *National Deaf-Blind Child Count* (NCDB, 2013), which includes data on

children who are deaf-blind from birth through age 21 in every state, indicate that many children are not referred to state deaf-blind projects until after age three. Child count data are collected by each state deaf-blind project and submitted to NCDB. NCDB compiles the data for the U.S. Department of Education's Office of Special Education Programs (OSEP). According to the child count, there are almost twice as many children in the age 3- to 6-year-old category than the 0- to 3-year-old category, suggesting that many children who are deaf-blind are not identified or referred to state deaf-blind projects until age 3 or older. This is especially evident for infants (birth to one year of age).



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## **Early Childhood Needs Survey**

To learn more about the state deaf-blind projects' early identification and intervention efforts, NCDB's Early Identification and Referral (EI&R) work group conducted a survey of state deaf-blind project directors in February 2008. The survey asked a number of questions about practices and programs related to early identification, natural environments, preschool inclusion, child outcomes, and early childhood transition. These categories are targeted by the U.S. Department of Education in the State Performance Plan (SPP) for early intervention and preschool programs. Of the 35 states that responded, 69% indicated that they did not believe their state projects had adequately identified infants with deaf-blindness prior to 1 year of age and 53% did not believe they had adequately identified children with deaf-blindness prior to 3 years of age. Great variation in the percentage of children who were identified before age 3 existed among states, ranging from 0% to 26% of the total number of children with deaf-blindness (NCDB, 2008).

The survey also asked respondents to indicate topical areas for which they would like to receive technical assistance (TA) from NCDB. The results clearly reflected that state deaf-blind projects were interested in receiving TA on strategies to improve early identification. Fifty-four percent of respondents indicated an interest in TA related to collaboration with the medical community in their states to improve early identification and 34% indicated a desire for TA on collaboration with their state's Part C and early hearing detection and intervention (EHDI) programs for the same purpose.

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## **Early Identification Focus Group**

To learn more about issues related to early identification, a focus group session was conducted with personnel from eight state deaf-blind projects in October 2008. The states were selected based on consistently high rates of early identification or demonstration of significant improvement in early identification from 2005 to 2007. This group represented a range of geographic, cultural, and population characteristics. The primary purpose of the focus group was to identify critical components of effective early identification efforts.

Several overarching themes emerged in the focus group session related to the early identification and referral of young children with deaf-blindness. First, although each state is unique, Part C programs play a key role in early identification and referral in most state deaf-blind projects. Rather than refer young children who are deaf-blind to state deaf-blind projects, health care and social service providers typically make referrals to Part C programs. Focus group participants emphasized the development of personal relationships with Part C coordinators as an essential component of early identification. They also described a number of specific strategies to facilitate the early identification and referral of young children with deaf-blindness, including conducting an annual census analysis to identify geographic areas within their states in which to intensify identification efforts; providing multiple avenues for parents and professionals to make referrals to the deaf-blind project; having someone on staff with expertise in the area of early intervention; and raising awareness of deaf-blindness and the state deaf-blind project by serving on their state's interagency coordinating committee for early childhood issues.

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Participants also stated that public awareness and referral materials play a significant role in the identification and referral process and should be tailored to specific audiences (e.g., educators, health care providers). During the session, participants shared a number of materials they had developed and suggested additional print and web-based resources they have found to be helpful in carrying out early identification activities. They stressed the importance of using previously developed materials when possible and sharing materials among state deaf-blind projects and the early intervention field.

### **Literature on Early Identification Research and Practices**

In addition to the survey and focus group, NCDB's Early Identification and Referral (EI&R) work group conducted an extensive literature review to find information related to early identification efforts both for children who are deaf-blind and for children with other types of disabilities. The literature fell into two categories: information about early identification initiatives occurring in other fields and promising practices to improve early identification and referral.

#### **Initiatives in Other Fields**

Professionals who work with young children who have disabilities other than deaf-blindness are also struggling with the need to find better ways to identify and provide services for children who require early intervention. For example, the standard for early detection of and intervention for hearing loss outlined in *Healthy People 2010* is as follows: (a) screening for hearing loss by age 1 month, (b) audiologic evaluation by

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age 3 months, and (c) enrollment in appropriate intervention services by age 6 months (U.S. Department of Health and Human Services, 2000). Although more than 95% of newborns in the U.S. are screened for hearing loss prior to hospital discharge (Joint Committee on Infant Hearing, 2007) and newborn hearing screening programs have reduced the average age of identification from 24–30 months to 2–3 months (Morton & Nance, 2006), many of these infants are not being served by their states' Part C programs. In 2012, only 58% of infants with known hearing loss were enrolled in Part C programs and, of these, approximately 33% were not enrolled until after 6 months of age (Centers for Disease Control and Prevention, 2012). A survey by the National Center for Hearing Assessment and Management (NCHAM) found that only 57% of state early hearing detection and intervention (EHDI) coordinators reported that they had "good or excellent coordination and cooperation" with their state's Part C program (White, 2006). NCHAM's director Karl White has written of the need for EHDI programs to find ways to improve collaboration with their state's Part C programs and for EHDI programs and other stakeholders (e.g., parents, audiologists, primary care physicians) to work with their Part C programs to establish well-defined eligibility criteria for deaf and hard-of-hearing children (2006).

Other groups are working to improve the identification of infants with vision loss. A national registry for children (birth to age three) with severe uncorrectable visual impairments, called Babies Count, has been established to collect data about the characteristics of this population (Hatton, Schwietz, Boyer, & Rychwalski, 2007). Information generated by the registry is likely to be of help to professionals working to better identify children who are deaf-blind. A 2013 report (Hatton et al., 2013) on 5,931



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children included in the registry noted that the most common types of vision loss were cortical visual impairment (CVI), retinopathy of prematurity (ROP), and optic nerve hypoplasia (ONH), with CVI being diagnosed later (mean age at diagnosis 6.8 months) than the other two conditions. Another interesting finding from the report is that 65% of the children showed evidence of developmental delay or additional disabilities.

Early identification of children with disabilities is a primary responsibility of pediatricians and other health care professionals who care for infants. In a 2007 policy statement, the Joint Committee on Infant Hearing (JCIH) emphasized the important role that pediatricians and other practitioners play in the process of early hearing disability detection and intervention. The statement includes a recommendation that “every infant with a confirmed hearing loss should have an evaluation by an ophthalmologist to document visual acuity and rule out concomitant or late onset vision disorders” (p. 908). A 2006 survey of primary care physicians, however, found that only 1% reported referring children with hearing loss to ophthalmologists (Moeller, White, & Shisler, 2006). Other recommendations by the JCIH (2007) relevant to efforts to improve early identification of infants who are deaf-blind include the following: (a) medical evaluation of infants with confirmed hearing loss in order to determine its etiology, identify related physical conditions, and provide recommendations for treatment and referral to other services; and (b) review of medical and family history for the presence of factors that indicate a risk for delayed-onset or progressive hearing loss.

The American Academy of Pediatrics Council on Children with

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Disabilities (2007) has also highlighted the important role that pediatric health care practitioners play in the process of early intervention and referral of children who have, or are at risk for, disabilities. Key recommendations from a policy statement by the Council on Children with Disabilities (2007) include the following: (a) surveillance and screening of all infants to identify disabilities or risk factors for delayed development, (b) prompt referral of these children to early intervention services, and (c) being aware of child and family services and resources available in the community and helping to coordinate the health component of these services.

### **Promising Practices**

A goal of the literature review was to identify promising practices and strategies to help NCDB's EI&R work group as it partnered with other entities to develop plans to improve early identification of children who are deaf-blind. Within the field of deaf-blindness, Deborah Chen of California State University, Northridge, has highlighted the importance of educating early interventionists (1997, 1998), and educators who work with children who are deaf or hard or hearing (2004) to understand deaf-blindness and recognize its associated signs and risk factors. However, most of the practices and strategies identified in the review are from outside of the field of deaf-blindness. As was found with the focus group of state deaf-blind project personnel, most published strategies involve forming positive relationships with potential referral sources and designing high quality public awareness and referral materials.

***Increasing referrals from health care providers.*** Researchers at TRACE (Tracking, Referral, and Assessment Center for Excellence) at the

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Orelena Hawks Puckett Institute have conducted a number of research syntheses investigating strategies to change physicians' referral and prescribing practices, and they have made recommendations about the applicability of these strategies for use by early intervention programs to increase the number of referrals they receive from health care providers. Dunst and Gorman (2006b) synthesized 42 studies of interventions intended to increase the rate and pattern of referrals by primary care physicians to specialists. They found that those most likely to be effective involved frequent face-to-face contact between physicians and program representatives, supported by written materials (e.g., program brochures, referral guidelines). Passive distribution of materials in the absence of face-to-face contact was not found to be effective.

Another synthesis analyzed 38 studies that evaluated characteristics of academic detailing, an educational outreach practice designed to influence physicians' prescribing practices (Clow, Dunst, Trivette, & Hamby, 2005). Although it is most commonly used by pharmaceutical companies, Clow and colleagues believe that academic detailing strategies hold promise as a means of increasing referrals by physicians to early intervention services. As with the study by Dunst and Gorman (2006b), this synthesis highlighted the effectiveness of regularly scheduled visits to physicians' practices by program representatives, supported by concise written and illustrated program materials (e.g., brochures). Other effective characteristics of academic detailing include emphasizing the benefits of referral in a way that is clear, concise, focused, and credible (e.g., referencing authoritative sources like the American Academy of Pediatrics) and providing timely and relevant feedback about the referred children to physicians who do make

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referrals. The importance of timely feedback to physicians regarding the children they refer was also highlighted by a separate synthesis (Dunst & Gorman, 2006a).

Dunst and Clow (2007) found that most Part C program child find activities do not conform to the strategies described above. Fifty-three percent of child find activities involve distribution of materials or public awareness campaigns, while strategies likely to be more effective such as outreach to referral sources and organizational collaborations constitute only 10% and 9% of activities, respectively. A useful outcome of this study was the development of a coding system that can be used by states or early intervention programs to ascertain whether their child find strategies are likely to be effective. It evaluates activities based on specific characteristics (e.g., type of intervention). TRACE has also created *Practice Guides* to help early intervention programs work more effectively with physicians to increase referrals (Dunst, 2006; Dunst, Trivette, & Hill, 2007).

***Creating materials.*** Although the above-mentioned studies suggest that distribution of materials in the absence of face-to-face contact is an ineffective strategy for increasing physician referrals, materials about a program's services and supports are important for reinforcing information provided during personal contacts with physicians (Clow et al., 2005), and they provide important information to families as well as to health care professionals. A study by Trivette, Rush, Dunst, and Sheldon (2006) found that postcards describing an early intervention program's services and supports sent by an early intervention program to parents of young children did significantly increase referrals by parents themselves, so it is possible that passive distribution of materials may have some effect with groups

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other than physicians.

Several studies have looked at characteristics of successful program materials. Davis and colleagues (2006) conducted a series of focus groups with parents, health care providers, and state newborn-screening professionals. Parents and professionals identified that written information should (a) be user-friendly and easy-to-read, (b) avoid excessive detail, and (c) highlight information that is relevant and practical. Parents also said that they want to receive information in person from a trusted health care provider in combination with a brochure they can take home.

An evaluation of parent education brochures developed by state newborn-screening programs (Arnold et al., 2006) found that the level of reading difficulty of most of the brochures was too high and nearly all could be made more user-friendly. As part of this study, the authors developed an evaluation instrument consisting of 22 characteristics of user-friendly materials categorized by layout, illustration, clarity of presentation, and cultural appropriateness, which may be useful to anyone developing publications of this type.

## **Current EI&R Initiative Efforts**

Following completion of the state deaf-blind project survey, the focus group session with state deaf-blind project personnel, and the extensive literature review, NCDB's Early Identification and Referral (EI&R) work group initiated a program of activities designed to assist state deaf-blind projects to improve early identification and subsequent referral of infants and toddlers with deaf-blindness. These efforts have occurred in two phases.

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Phase 1 involved the development of a framework to support state deaf-blind project EI&R efforts. The framework has four primary components: (a) a process to determine whether children with deaf-blindness are under identified or under referred in a specific state, (b) analysis of possible causes of under identification or under referral when they occur, (c) use of likelihood impact data to identify a state system (e.g., Part C, health care agencies, community agencies) to target for improvement of early identification and referral, and (d) implementation of evidence-based strategies to address identified causes and increase identification and referral. This phase of the work resulted in a self-assessment guide that includes a collection of online resources known as the "Toolbox," to assist identification and referral activities.

Phase 2, which is currently ongoing, involves the development of a tiered system of universal, targeted, and intensive technical assistance (TA) to provide systematic support to state deaf-blind projects. Throughout each phase, NCDB and the state deaf-blind projects have also worked to establish partnerships with professionals and agencies from disciplines beyond the field of deaf-blindness who are involved in early identification at local, regional, state and national levels.

## **Resources**

### ***Early Identification and Referral Self-Assessment Guide***

(Purvis et al., 2013). The self-assessment guide, which uses data-based decision making to improve early identification and referral, is part of the framework described above. Following its development in 2011, ten state deaf-blind projects were selected through an application process to test the guide the following year. NCDB's Early Identification and Referral (EI&R)

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team provided technical assistance throughout the testing process. Based on field experience, the model was revised and an online version made available to all state deaf-blind projects early in 2013.

Since that time, at least 18 more state deaf-blind projects have completed the self-assessment process as the first step in their efforts to improve early identification and referral of infants and toddlers with combined vision and hearing loss in their states. Eleven projects are currently engaged in the next step in the process, the development or implementation of an action plan. The NCDB EI&R team has provided varying levels of TA to these projects as they have moved through the early identification and referral framework.

***Online Toolbox of EI&R Resources*** NCDB and state deaf-blind project personnel (collectively known as the National Deaf-Blind TA Network) have established a repository of resources that state deaf-blind projects can use in their work to impact individual state systems. It is intended for use in conjunction with the EI&R Self-Assessment Guide and is available on NCDB's website in a content-specific group space. The toolbox format was informed by knowledge gained from the literature review and promising practices described earlier. Resources are organized first by whether they address identification or referral and are then aligned according to particular early intervention systems within a state (Part C, EHDI, a medical system, or other community programs) and the evidence-based practices for which they are likely to be most effective.

Task-specific work groups that include representatives from the National Deaf-Blind TA Network are currently collaborating with early intervention, medical, and family networks to revise existing EI&R materials

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and develop new ones. Concerted efforts have been made to avoid duplication and ensure that what we have learned about best practices in early identification and referral is reflected in the materials. In response to requests from state deaf-blind projects and early intervention personnel, the following materials are being developed: a list of conditions that put infants at risk for combined vision and hearing loss (includes medical billing codes), fact sheets that present NCDB National Child Count data specific to children birth through two, and an informational brochure that provides a visual profile of infants and toddlers with deaf-blindness. Moving forward, ongoing contributions from a variety of stakeholders will make certain that state deaf-blind projects have access to an ever richer body of materials targeted to specific audiences or issues.

### **Technical Assistance**

A tiered system of technical assistance (TA) supports the ongoing and broadening early identification and referral work in which state deaf-blind projects are engaged. As of the summer of 2014, this system includes three categories of TA.

At the **universal TA** level, state deaf-blind projects can access the EI&R self-assessment guide and the toolbox of EI&R resources, available online in a designated group space on NCDB's website. The group space also includes a place to upload mutually beneficial materials, areas where individuals can collaborate to create or share materials, and a forum for online discussion. Basic information and assistance from NCDB's EI&R team is also available as part of universal TA. It can be requested through a



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simple online form and is provided free of charge via email, telephone calls, or web meetings.

When additional supports are necessary, **targeted TA** provides opportunities to address early identification and referral issues using a more sustained approach. Targeted TA is designed to respond to specific requests or needs. It includes a) state-specific activities and b) collaborative activities. *State-specific targeted TA* expands on universal TA activities with a state deaf-blind project or early intervention system in a single state. It typically occurs over an extended period of time and includes regularly scheduled consultation, meeting facilitation, and coaching. *Collaborative targeted TA* consists of activities that address identification and referral issues across states. Its purpose is to build the capacity of all state deaf-blind projects to impact their states' early intervention systems by connecting individuals with common interests or challenges. Collaborative targeted TA includes task-specific work groups, meeting facilitation, and formal presentations. Activities take place at a distance, primarily by phone and small- or large-group web meetings.

Recognizing the challenges associated with implementing practices that result in long-term systemic change, NCDB has recently launched an **intensive TA** initiative. This highest level of TA is provided free of charge to a state deaf-blind project following an application process to determine state readiness and capacity. In addition to universal and targeted TA activities, intensive TA provides for onsite support at critical points during the implementation process. One state deaf-blind project is currently participating in this initiative and NCDB plans to select another state to participate during the next fiscal year.

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## **Partnerships**

NCDB has worked diligently to partner with entities outside the field of deaf-blindness to raise awareness of the importance of early identification and referral of children who are deaf-blind and share strategies that will improve identification of all children with disabilities. Potential national partners include the National Center for Hearing Assessment and Management, the Early Hearing Detection and Intervention (EHDI) Program at the Centers for Disease Control and Prevention (CDC), American Printing House for the Blind's Babies Count Project, and the Early Childhood Technical Assistance Center (ECTA).

As a first step, NCDB increased knowledge of EHDI program structure and resources by attending the 2012 national EHDI conference and by presenting at the conference in 2013. As part of the initiative work described in the previous section, targeted information materials are being developed that EHDI and Part C programs will be able to use to increase awareness of the significance of combined vision and hearing loss and the benefits of referral to appropriate intervention services. A pilot project in collaboration with EHDI or Part C personnel to promote use of these materials may be developed in the future.

Just as NCDB is working to partner with national organizations, individual state deaf-blind projects are working to form relationships with referral systems within their states. These include Part C early intervention programs, Early Hearing Detection and Intervention (EHDI) programs, hospitals, medical professionals, and other community programs serving children birth through two years of age and their families (e.g. Early Head Start, organizations serving children who have vision or hearing loss).

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Building rapport and establishing credibility with primary referral sources creates a strong foundation from which to forge partnerships that will systemically impact practitioner behavior, practices and policies. This collaborative approach aligns with methods being promoted by the U.S. Office of Special Education Programs (OSEP) and has been recognized as one that may serve as an effective model to help ensure that low-incidence disabilities are included in larger state initiatives.

In addition, NCDB is hoping to organize and support a national early identification and referral technical assistance team consisting of individuals from state deaf-blind projects who have early intervention experience and expertise. A national TA team could maintain and expand the technical assistance capacity of the current NCDB EI&R team and strengthen the national deaf-blind technical assistance network. It could utilize evaluation data to improve the implementation of evidence-based identification and referral practices and ensure that high quality TA is continually available to state deaf-blind projects involved in the EI&R self-assessment process and the early intervention systems they are working to change. A national TA team could also develop materials that families and early intervention providers can access to improve learning outcomes for infants and toddlers with combined vision and hearing loss, which will be critical as an ever increasing number of children are identified and referred for early intervention and family support.

### **Conclusion**

Early identification of children with combined vision and hearing loss will increase opportunities for families and early intervention personnel to connect with their state deaf-blind projects, not for the purpose of placing a

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“label” on a child but to provide timely early intervention and technical assistance. Increased referrals to state deaf-blind projects will ensure that each child is counted and that each family has access to technical assistance designed to provide the specialized resources and support needed for their child. Appropriate early intervention services help maximize learning during a child’s critical early years and lead to improved physical, communication, cognitive, social, and emotional development. These are outcomes that NCDB is committed to achieving through its focus on early identification and intervention.

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