Early Identification
of Infants Who Are Deaf-Blind

NCDB
National Consortium on Deaf-Blindness

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, 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, now called the Early Identification Work Group (EIWG), narrowed its focus to efforts designed to promote early

identification and referral. This report describes the findings that led to this decision and discusses future directions for NCDB as it forms partnerships to develop and evaluate initiatives to improve early identification of children who are deaf-blind.

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

strong consensus that early intervention is crucial (Murdoch, 2004), but findings from the *National Deaf-Blind Child Count* (NCDB, 2008), 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 referred to state deaf-blind projects until age 3 or older.

2007 Deaf-Blind Child Count
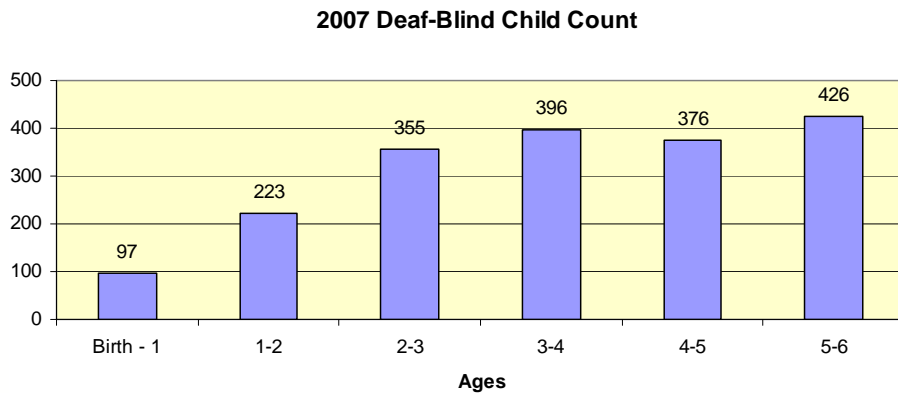
Early Childhood Needs Survey

To learn more about the state deaf-blind projects' early identification and intervention efforts, NCDB's Early Identification Work Group (EIWG) 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 do not believe their state projects have adequately identified infants who are deaf-blind prior to 1 year of age, and 53% do not believe they have adequately identified children who are deaf-blind prior to 3 years of age. Great variation in the percentage of children who are identified before age 3 exists among states, ranging from 0% to 26% of the total number of children who are deaf-blind (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 reflect that state deaf-blind projects are interested in receiving TA on strategies to improve early identification. Fifty-four percent of respondents indicated interest in TA related to collaboration with the medical community in their states to improve early identification, and 34% would like TA on collaboration with their state's Part C and early hearing detection and intervention (EHDI) programs for the same purpose.

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. Also, this group had a variety of geographic, cultural, and population characteristics. The primary purpose of

the focus group was to identify critical components of effective early identification efforts in these states.

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.

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 with the broader field of deaf-blindness.

Literature on Early Identification Research and Practices

In addition to the survey and focus group, the EIWG 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 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 2006, only 53% of infants with known hearing loss were enrolled in Part C programs and, of these, approximately 30% were not enrolled until after 6 months of age (Centers for Disease Control and Prevention, 2008). 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 recent report (Hatton et al., 2007) on 2,155 children included in the registry noted that the most common types of vision loss were cortical visual impairment (CVI), retinopathy of prematurity, and optic nerve

hypoplasia, with CVI being diagnosed later (mean age at diagnosis 7.6 months) than the other two conditions. Another interesting finding from the report is that 68% 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 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 recent policy statement (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 the EIWG as it partners 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

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 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 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.

Future Directions

Having completed the state deaf-blind project survey, the focus group session with state deaf-blind project personnel, and an extensive literature

review, NCDB's Early Identification Work Group will now use what we have learned to design and initiate activities to assist state deaf-blind projects to improve early identification and subsequent referral to state deaf-blind projects. These activities fall into the following two categories: (a) development of a model framework for states to use to analyze their early identification efforts and determine specific strategies to improve early identification, and (b) form relationships with professionals and agencies involved in early identification efforts in other disciplines to find ways to improve the identification of children with disabilities during infancy.

The model development project will involve the creation and testing of a framework that will have three primary components: (a) a process to determine whether children with deaf-blindness are underidentified in a specific state, (b) analysis of possible causes of underidentification if it is determined to be occurring, and (c) strategies to improve identification that will address any identified causes. We plan to develop and test the model during the 2009–2010 school year and revise and implement the model with additional states during the 2010–2011 school year. An application process will be used to recruit state deaf-blind projects to participate in this project.

In addition to the model development project carried out with state deaf-blind projects, NCDB will also seek to join forces with national partners such as the National Center for Hearing Assessment and Management, the Early Hearing Detection and Intervention Program at the Centers for Disease Control and Prevention, the Babies Count Project, and the National Early Childhood Technical Assistance Center. By partnering with other entities, we

hope to raise awareness of the importance of early identification of children who are deaf-blind and to share knowledge and strategies that will improve identification of all children with disabilities.

The 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 purposes of placing a "label" on a child but to provide timely early intervention and technical assistance. Referral 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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