



July 2006

Deaf-Blind Child Counts: Issues and Challenges

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Congress has supported a federal program for children who are deaf-blind since the late 1960s. Currently, this program includes projects to deliver national and state technical assistance (TA), as well as a national information and dissemination clearinghouse. Children with deaf-blindness (DB) represent one of the lowest incidence, yet most diverse groups of learners receiving early intervention and special education services. They make up an extremely heterogeneous group whose sensory losses are frequently accompanied by additional physical or cognitive disabilities, complex medical needs and/or behavior challenges.

Deaf-blindness has a tremendous impact on a child's ability to understand and interact with the world. Quality programming requires early intervention and educational and transition services that acknowledge the impact of DB on the child's unique needs and learning style and incorporate strategies that address the child's DB. Concerns about underidentification of DB and its resulting unique intervention requirements has been a consistent problem and one which can result in a lack of, or delay in receiving, appropriate intervention and instruction critical to children's early development.

For more than 20 years, state and multi-state deaf-blind projects have been gathering annual child count data on the numbers of children with DB in order to supplement federal Child Count data for the Office of Special Education Programs (OSEP), which only include children for whom DB is a primary disability. The projects' data collection is facilitated by the National Technical Assistance Consortium for Children and Youth with Deaf-Blindness (NTAC). Specifically, NTAC is charged with gathering, maintaining and analyzing demographic information on children who are deaf-blind for the purpose of developing project priorities based on data documenting the needs of these children. Consistent with the priorities under which NTAC and the other deaf-blind projects are funded, this annual child count, commonly referred to as the "census," is used to identify national and state TA needs for children who are deaf-blind, their families and the service providers and systems that serve them. NTAC child count information is also used to identify research needs, develop personnel preparation programs and target national and state product development and dissemination activities. To ensure clarity, the

two counts will henceforth be referred to within this document as the “OSEP Child Count” and the “NTAC census.”

According to OSEP Child Count figures for the 2004 academic year, there were 1,977 children ages 3-21 with DB.¹ The NTAC census for the same year, however, indicates that there were 8,999 children with DB when including those for whom DB was a secondary or tertiary disability, or well over *four times* as many children.²

The purpose of this study is to describe some of the ways deaf-blind projects collect NTAC census data, compare OSEP Child Count and NTAC census data for the ten states included in this study and identify issues and concerns raised by deaf-blind project directors related to the discrepancy between OSEP Child Count and NTAC census figures. Project Forum at the National Association of State Directors of Special Education (NASDSE) conducted this study as part of its cooperative agreement with OSEP.

Background on NTAC Census

The NTAC census began in the early 1980s in order to supplement OSEP’s Child Count data, because that data clearly did not include the total number of children with DB.³ In the fall of each calendar year, NTAC sends out reporting materials to the deaf-blind projects serving the 50 states and two U.S. territories.⁴ Materials consist of a cover letter; NTAC’s definition of DB; instructions describing each item on the census (including demographic information, etiology of condition, date of most recent vision and hearing exams, primary classification of vision and hearing impairments, primary disability category, educational setting, exiting information, and living setting); and a spreadsheet for data reporting purposes (although most deaf-blind projects now submit data electronically). This information, which needs to be returned to NTAC by April 1st, is intended to serve as a “snapshot” of children identified with DB in each state as of December 1st of the preceding year. Although no longer the case, NTAC census data was used by OSEP in the past to help determine the size of grants awarded to state and multi-state deaf-blind projects.

¹ Recent OSEP Child Count data is available at www.ideadata.org.

² Data from the most recent NTAC census is available at http://www.tr.wou.edu/ntac/index.cfm?path=publications/publications_census.html.

³ John Killoran and Joe McNulty of NTAC generously shared information with Project Forum staff relating to the NTAC census, as well as information on the history of the state/multi-state deaf-blind projects. Much of this information can be found in Killoran, J. (2005). *The annual count of children and youth who are deaf-blind: Instructions, definitions and coding form*. Monmouth, OR: The National Technical Assistance Consortium for Children and Youth who are Deaf-Blind, The Teaching Research Institute, Western Oregon University. They also reviewed an earlier version of this document.

⁴ The 48 projects cover 52 states and territories. Most states have their own projects. However, the New England Center Deafblind Project serves Connecticut, Maine, Massachusetts and New Hampshire; and Puerto Rico and the Pacific Basin share a project.

Federal and NTAC Definitions of Deaf-Blindness

Current IDEA regulations provide the following definition for deaf-blindness:

Deaf-blindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for children with deafness or children with blindness [34 CFR §300.7(c)(2)].⁵

Regulations pertaining to annual reporting requirements also include the following reference to the identification of children with DB:

- (1) If a child has only two disabilities and those disabilities are deafness and blindness, and the child is not reported as having a developmental delay, that child must be reported under the category “deaf-blindness.”*
- (2) A child who has more than one disability and is not reported as having deaf-blindness or as having a developmental delay must be reported under the category “multiple disabilities” [34 CFR §300.751(f)(1)(2)].*

Because the majority of children with DB *do* have other disabilities as well, most are included in the OSEP Child Count as having multiple disabilities as opposed to DB.

NTAC’s definition of DB is similar to the federal definition, though not identical:

The term “children with deaf-blindness” means children and youth having auditory and visual impairments, the combination of which creates such severe communication and other developmental and learning needs that they cannot be appropriately educated without special education and related services, beyond those that would be provided solely for children with hearing impairments, visual impairments, or severe disabilities, to address their educational needs due to these concurrent disabilities. This term also means infants and toddlers with deaf-blindness.⁶

Although NTAC’s definition is consistent with that used in IDEA, each deaf-blind project has the discretion to determine eligibility for project services under this definition. This is consistent with the discretion states have in determining state eligibility criteria for the other IDEA disability categories.

⁵ Final regulations for the new law were pending at the time of this report.

⁶ NTAC also provides the following definition for “infants and toddlers with deaf-blindness”: “The term...means individuals from birth through age 2 who are experiencing developmental delays in hearing *and* vision, have a diagnosed physical or mental condition that has a high probability of resulting in developmental delays in hearing *and* vision, or are at risk of having substantial developmental delays in hearing *and* vision if early intervention services are not provided.”

Significantly, the National Coalition on Deaf-Blindness and several other organizations such as the Helen Keller National Center have recommended that the IDEA 2004 regulations include a revision to the federal definition that would stipulate that *any* child with concomitant vision and hearing loss, including children with additional disabilities, be automatically identified with DB.⁷ Several revisions to the NTAC census elements, including the definition, are pending awaiting publication of regulatory revisions resulting from the passage of IDEA 2004.⁸

Methodology

Data collection for this document took place in two phases. First, Project Forum selected ten states for in-depth analysis – *Delaware, Kansas, Kentucky, Massachusetts, Minnesota, North Carolina, Nebraska, New Mexico, Utah and Washington* – and compared Child Count data and NTAC census data for each. Selection of states was intended to be geographically representative of the U.S. However, because OSEP Child Count figures for DB are sometimes suppressed in order to protect the confidentiality of individual students, Project Forum selected states from within the pool of 21 states for whom OSEP Child Count figures were available. These findings are presented in the section of this document titled “OSEP Child Count as Compared to NTAC Census Data” (see page 7). Second, Project Forum, in collaboration with staff from NTAC and The National Information Clearinghouse on Children Who Are Deaf-Blind (DB-LINK), developed an interview protocol regarding issues relating to the discrepancy in figures between OSEP Child Count and the NTAC census (See Appendix A for a copy of the interview protocol).⁹ Deaf-blind project directors from the ten states were interviewed during the period February through May, 2006.¹⁰ Interviews were transcribed verbatim and analyzed using ATLAS.ti – a software program designed to aid in the analysis of qualitative data.

Findings

Collecting NTAC Census Data

⁷ This information was provided by Joe McNulty of the Helen Keller National Center. Their website is located at www.hknc.org.

⁸ The purpose of NTAC’s proposed revisions is to align language and terminology used in the census to that in IDEA 2004 and specific Section 618 reporting requirements. The proposed revisions would allow for a more accurate comparison of data between NTAC and OSEP’s respective December 1 child counts.

⁹ Kathleen Stremel of NTAC and John Reiman and Gail Leslie of DB-LINK provided invaluable help developing Project Forum’s interview protocol and also reviewed an earlier version of this document.

¹⁰ Project Forum gratefully acknowledges the following individuals for participating in an interview and reviewing an earlier version of this document: Peggy Lashbrook, Coordinator, Technical Assistance and Training for Service Providers of Children with Deafblindness in Delaware; Joan Houghton, Director, The Kansas Project for Children and Youth who are Deaf-Blind; Diane Haynes, State Coordinator, Kentucky Services for Children Who Are Deaf-Blind; Tracy Evans Luiselli, Project Coordinator, New England Center Deafblind Project; Eric Kloos, Project Director, Minnesota Deafblind Technical Assistance Project; Teresa Coonts, Project Coordinator, Nebraska Deaf-Blind Project; Molly McLaughlin, Project Coordinator, Center for Development and Disability’s Project for New Mexico Children and Youth Who Are Deaf-Blind; Chris Jones, Coordinator, North Carolina Project for Children and Young Adults Who Are Deaf-Blind; Darla Fowers, Project Director, Utah Deafblind Project; and Nancy Hatfield, Project Co-Director, Washington State Services for Children with Deaf-Blindness.

Because state deaf-blind projects have varied infrastructures and goals, project directors described a wide range of methodologies for collecting NTAC census data.¹¹ For example, although most interviewees described sending out an annual mailing as part of their DB projects' processes for updating NTAC census data, they requested information from varied sources. In most states, updated information is solicited primarily from the special education directors of local education agencies (LEAs) or their designees. However, other sources of data include school administrators at individual schools, classroom teachers, teachers of the visually impaired, teachers of the deaf and hard of hearing, families, Part C service providers, Section 619 programs, schools for the deaf and blind, charter schools, Parent Training and Information Centers (PTICs) and/or private programs. Mailings usually include packets of materials provided by NTAC, but these materials are occasionally adapted to better meet each deaf-blind project's unique needs. For example, in order to improve response rates, *Washington* includes a cover letter from the state director of special education and *Minnesota* offers respondents the opportunity to receive additional information and/or TA. Other interviewees reported using the federal or state definition of DB as opposed to the NTAC definition. *Nebraska* and *New Mexico* noted that the census form can be downloaded from the project's website.

In addition to mailings, several interviewees described other means of gathering updated information. For instance, *Kentucky* has a part-time family services coordinator whose responsibility it is to collect and update information via phone or in person. Information is also collected on an ongoing basis for children whose teachers and/or related service providers are receiving TA from the project. Families in *Kentucky* sign a medical release form and the family services coordinator then requests updated medical information (i.e., vision and hearing evaluations) directly from doctors. Similarly, *Massachusetts'* education consultants (deaf-blind project employees) review census data on an annual basis, frequently updating information during face-to-face meetings. The *Utah* state legislature has mandated that all deaf-blind services be coordinated under a single umbrella agency. Regional consultants (paid through state dollars) update information annually for children included on the NTAC census, as well as meet with classroom teachers on a monthly basis. *Minnesota* supplements its mailed census with information gathered during TA visits to schools and homes. *Kansas'* project—which serves as the fiscal agent for a legislative fund tied to children with DB—conducts an *additional* census every three years that is separate from the NTAC census or Child Count.

Deaf-blind projects also report engaging in extensive outreach efforts designed to increase awareness of DB on the part of professionals throughout the state. Some project coordinators mentioned initiatives to help improve identification of children with, or at risk of, DB. For example, *Kentucky's* project has developed a new initiative with the medical community and is hosting lecture series at medical schools. *Kentucky* is also developing a brochure for the medical community regarding early identification of DB and, in response to the established risk list for Part C that includes 294 conditions, working with the medical community to “cross-walk” those conditions which are considered “red flags” for vision and/or hearing loss. In order to increase

¹¹ However, differences in data collection methodologies are not unique to NTAC's census, but are also evident across states in their collection of OSEP's December 1 Child Count data.

the number of children identified with DB, *Kansas*' project regularly conducts "sweeps" (i.e., reviews building-level records of all students identified with hearing impairments, visual impairments or multiple disabilities in order to determine if any meet the project's eligibility criteria for DB). Deaf-blind projects also reported disseminating information about DB via workshops, divisional meetings, project websites and/or partnerships with institutions of higher education (IHEs). *Minnesota* provides medical and parent information to pediatric ophthalmologists, audiologists and geneticists at major children's health centers.

Interviewees report that deaf-blind projects are continually receiving new referrals. These referrals come from LEAs, principals, teachers, parents, outreach programs (e.g., outreach staff at *New Mexico's* School for the Deaf), medical professionals (e.g., ophthalmologists, audiologists, developmental pediatricians) and Part C programs. According to *Kentucky's* program director, "New referrals often come because we're in a classroom, and while we're there, particularly if it's a teacher or LEA we haven't worked with before, they'll ask us to take a look at another student."

Significantly, with the exception of *Minnesota's* and *Utah's* programs, others reported that they were currently unable to use newborn hearing screening (NBHS) data to help identify infants with DB in their states. Several expressed concerns relating to Health Insurance Portability and Accountability Act (HIPAA) restrictions.¹² Many interviewees expressed frustration with this inability to access results of the NBHS. In the words of one, "Medical professionals feel they can't come forward because of confidentiality...and so our hands are tied." Another stressed that "follow-up isn't occurring as it should." The interviewee from *Nebraska* noted that the state's project is working closely with the director of the state's NBHS to establish a mechanism that will ensure that children who fail the test will receive appropriate follow-up services. The interviewee from *New Mexico* also noted that the project is exploring ways to access results from the state's newborn vision screening (NBVS).

Although many project directors described frustration with the lack of collaboration/coordination between the Child Count and NTAC census data collection processes in their states, more than half of the state interviewees reported that they *were* in fact able to access at least some state Child Count data and use it as a part of their NTAC census data collection process. For instance, both the *Minnesota* and *New Mexico* deaf-blind projects begin their data collection process by first reviewing Child Count data and the interviewee from *Delaware* described a system whereby Child Count and NTAC census data collection are actually combined into a single process. Significantly, almost all of these projects are housed at the SEA, permitting project directors to access data without violating HIPAA confidentiality requirements.

¹² According to the U.S. Department of Health and Human Services (HHS), "The Standards for Privacy of Individually Identifiable Health Information ('Privacy Rule') establishes for the first time, a set of national standards for the protection of certain health information. HHS issues the Privacy Rule to implement the requirement of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). The privacy rule standards address the use and disclosure of individuals' health information...as well as standards for individuals' privacy rights to understand and control how their health information is used." More information about HIPAA can be found at www.hhs.gov/ocr/privacysummary.pdf.

Definitions and Eligibility Criteria for Inclusion within the NTAC Census

Most deaf-blind projects interviewed (MN, MN, NC, NE, NM, UT, WA) use the NTAC definition of DB or the federal definition to determine eligibility for inclusion within the NTAC census (and in many cases, to determine eligibility for deaf-blind project services). Neither definition includes specific cut-offs regarding severity of hearing and/or visual impairment for inclusion. *Massachusetts* also uses the NTAC definition, but reports being “more lenient with a child who has fluctuating hearing loss based on ear infections, when it’s not really clear whether that child is going to have hearing loss long-term.” *Kentucky’s* deaf-blind project uses both the state’s definition of DB and the Helen Keller National Center’s definition, neither of which include specific cut-offs. *Kansas, Nebraska* and *Utah’s* deaf-blind projects, while using the federal or NTAC definitions for DB, also include specific cut-offs for vision and hearing impairment as part of their eligibility criteria and in the case of *Utah’s* project, these cut-offs are actually more stringent than the state’s.

While most interviewees reported that formal vision and hearing assessments (i.e., assessments conducted by ophthalmologists and audiologists) were preferable to functional assessments¹³, children for whom only functional vision and hearing assessments were available could also be included on the NTAC census – particularly in the case of children with severe multiple disabilities. Exceptions to this include *Kansas, North Carolina* and *Nebraska*, which all require formal audiological and ophthalmological assessment.¹⁴ Among those states accepting functional assessments, the percentage of children lacking formal assessments varied significantly. For example, the interviewee from *Massachusetts* estimated that only 10% of children included on the NTAC census lacked formal assessments, whereas the interviewee from *Kentucky* estimated that as many as 35% lacked formal assessments. The interviewee from *Washington* noted that “we press a lot harder than some states for formal audiological [assessments] because we feel that sometimes [LEAs] use that as an excuse when they actually could get some audiological or ophthalmological results,” and the interviewee from *Kentucky* noted that the deaf-blind project works hard to identify audiologists across the state who will “work harder” to get formal assessment results from children with severe multiple disabilities.

In terms of documentation, interviewees from five states (KS, KY, MN, NC, WA) noted that verification of medical exams was required, although states usually do not require such verification for children at risk for DB.

OSEP Child Count as Compared to NTAC Census Data

Table 1 compares OSEP Child Count and NTAC census data for 2004 for the 10 states studied, as well as for all 50 states and territories combined. Because OSEP data is not available for

¹³ Functional assessments are systematic procedures to determine how students are functionally using their vision and hearing in daily life.

¹⁴ It should be noted that this variability of eligibility requirements across state/multi-state projects, including functional versus formal assessments, is consistent with the variability across state’s definitions and eligibility criteria for the other IDEA disability categories.

children ages birth through two, and is frequently suppressed for children ages 3-5 due to small size, the figures provided below for both OSEP Child Count and NTAC census data only include children ages 6-21. When children ages birth through five are included, total numbers of children with DB are significantly higher.

Table 1 – OSEP Child Count and NTAC Census Figures for Children with Deaf-Blindness Ages 6-21

State	OSEP Child Count 2004	NTAC Census 2004
Delaware	42	44
Kansas	17	75
Kentucky	12	116
Massachusetts	265	135
Minnesota	53	168
North Carolina	26	389
Nebraska	8	104
New Mexico	23	108
Utah	161	81
Washington	37	157
Total for all 50 states and territories	1,725	7,972

Reasons for Discrepancies

DB project directors offered a number of reasons for discrepancies between OSEP Child Count and NTAC census figures. Most importantly, interviewees blamed the discrepancy on the facts that the OSEP Child Count only includes children for whom DB is a primary disability and that Individualized Education Program (IEP) teams in many states, due to current federal definitions that appear to require children with additional disabilities be identified as multiply disabled, are more likely to identify children as having multiple disabilities than DB. Interviewees also frequently mentioned the “stigma” associated with DB, creating hesitancy on the part of IEP teams to identify a child as such and ignorance on the part of professionals regarding the range of conditions included within the definition of DB (e.g., many people are unaware that a child does not have to be legally blind to be eligible for the category of DB). In the words of one interviewee, “People have seen DB as Helen Keller and if the student doesn’t look like Helen Keller, they don’t refer.” Several interviewees also mentioned the common misperceptions that “services are driven by the disability,” and that more educational and related services are available to a child identified with multiple disabilities than with DB. Other interviewees mentioned the fact that many LEAs lack professional staff with expertise in DB, and that IEP teams are consequently unwilling to identify children with DB for fear that they will not be able to provide appropriate educational supports to them (e.g., teachers certified in DB and/or communication interveners). Other reasons cited for discrepancies include the following:

- lack of consistency across LEAs and IEP teams in terms of how DB is defined;

- refusal on the part of LEAs to identify children with DB without a formal audiological assessment (a practice that automatically excludes numerous children with severe multiple disabilities for whom a formal assessment is not possible);
- lack of personnel preparation options, particularly in small states and rural areas;
- fiscal incentives to identify children with disabilities other than DB; and
- confidentiality requirements (e.g., HIPAA) which prevent the sharing of Child Count data with deaf-blind projects that are not housed at the SEA.

The interviewee from *Delaware* (the state in which OSEP Child Count and NTAC figures were the most similar) suggested that one possible reason for this was that children with DB are funded at a higher rate than children with all other disabilities except autism (i.e., for every four children with DB, there is both a teacher and paraprofessional assigned). Consequently, there is a fiscal incentive to identify children with DB as opposed to multiple disabilities.

Finally, as illustrated in Table 1 (See above), although OSEP Child Count figures were much *lower* than NTAC census figures in most cases, OSEP Child Count figures were actually *higher* in the states of *Massachusetts* and *Utah*. Project Forum staff spoke with data managers for both states to ensure that reporting had been accurate and were given the following explanations:

- *Massachusetts* has a code for “sensory impaired deafblind,” and it appears that many IEP teams were incorrectly using this classification for children who were actually either “sensory impaired blind” or “sensory impaired hearing.”
- *Utah’s* recent reevaluation of students resulted in a significant drop in OSEP Child Count’s numbers of children identified with DB (from 161 in 2004 to only 85 in 2005). There was a corresponding *increase* in the number of children identified with multiple disabilities or deaf and hearing impaired, suggesting that they had originally been misidentified. Other possible reasons for this discrepancy include the fact that state eligibility criteria ask for functional *or* clinical assessment (not both), whereas the project requires both functional *and* clinical assessments to verify vision and hearing impairments, and that there are fiscal incentives to identify children with DB (i.e., each child so identified usually receives the services of a one-on-one communication intervener, which, in the words of the interviewee, “opened a floodgate of kids” identified with DB).

Practical Implications of Discrepancy in Figures

According to interviewees, the most troubling implication of the discrepancy between OSEP Child Count and NTAC census figures is that children with DB are not necessarily receiving needed services and supports. As one interviewee noted, children with DB are most likely to be identified as multiply disabled and “children with multiple disabilities are not only not getting DB services, most often they’re not getting services from a teacher of the blind and visually impaired or [teacher of the] deaf and hard of hearing at the itinerant level. Their vision and hearing is not being addressed.” As another interviewee suggested, if children were identified

with DB, “it would just kind of clue the whole team into looking at that child a little differently” in terms of educational services, intervention and instruction, assessment and curriculum. For example, the strategies used for students with dual sensory impairments are quite different than those used for either visual impairment or hearing impairment alone. One interviewee noted that this problem is compounded for very young children, who often fail to receive early and appropriate identification.

Several interviewees said that the discrepancy in counts also has serious implications for higher education, suggesting that more money would be available for preparing professionals in the field of DB and/or moderate/severe disabilities if OSEP Child Count numbers were higher. Interviewees also mentioned the negative impact of low OSEP Child Count figures on inservice opportunities and the training of paraprofessionals. Other areas of concern noted were the inadequacy of available research dollars and the difficulty of getting results on state assessments for *all* students identified with DB, not just those for whom DB is a primary disability.

According to one interviewee, OSEP Child Count figures “grossly understate the significance or level of need that’s out there.” Several interviewees, however, particularly those whose deaf-blind projects are housed at the SEA, make efforts to ensure that NTAC census figures, not just OSEP Child Count figures, are used for state-wide planning purposes. Significantly, although several interviewees feel that even their state-level NTAC census underestimate the total number of children with DB, others are confident that the NTAC census does in fact capture all children with DB in their states. Furthermore, although they were definitely in the minority, interviewees from two projects noted that they do not feel that the discrepancy between OSEP Child Count and NTAC census figures has *any* negative practical impact on available resources for children with DB.

Recommendations

Deaf-blind project directors shared a number of policy recommendations, although they did not always agree with one another. For example, half of interviewees recommended that there be a single definition for DB used by all states (both departments of education and deaf-blind projects) “because otherwise you have data that you can’t aggregate.” Others, however, felt that a common definition was unnecessary and some were concerned that a single definition that included explicit “cut-off” criteria might actually result in the unfair exclusion of some children. Similarly, many interviewees recommended that federal and/or state definitions of DB require that any child with both visual and hearing impairments be automatically identified with DB rather than multiple disabilities or any other disability category. A few interviewees disagreed, however, stressing the importance of preserving the IEP team’s right to determine the most appropriate disability category for each child on a case-by-case basis. In the words of one: “Most of my colleagues are probably wanting all those kids to be totally identified as DB, and part of me says, ‘That’s really an IEP team decision. We can’t influence that too much. We can educate people on the impact of dual sensory loss, but we cannot make that decision.’” Most interviewees also supported the use of a mandatory secondary disability field at state and local levels, although a few cautioned that this would not entirely solve the issue of generating a

complete count of children with DB, since IEP teams could still opt to identify disabilities other than DB as secondary (e.g., visual impairment or hearing impairment).

Other recommendations were less controversial. For instance, several states recommended that deaf-blind projects be housed at the SEA, giving projects a more powerful voice when it comes to education of children with DB. As one interviewee noted, “a lot of DB projects are not directly hooked into their departments of education.” Half of the interviewees also expressed a desire to see greater coordination between data collection processes related to state OSEP Child Count and those related to the NTAC census. For example, the *Massachusetts* Department of Education and the state’s deaf-blind project have agreed that it would be mutually beneficial for each child to be assigned a common identification number, enabling both the Department and the deaf-blind project to “look at the same kids.” One interviewee suggested that OSEP mandate that state departments of education and deaf-blind projects collaborate in this and other areas (e.g., inservice training for members of IEP teams). Another interviewee recommended that OSEP Child Count and the NTAC census use “the same language, same codes, same everything” to better facilitate the sharing of information.¹⁵ Another common theme was the need for data on DB that can be aggregated across states for research purposes (e.g., in order to better understand how demographics are shifting and whether or not outcomes are changing over time). As one interviewee noted, without a common cross-state definition of DB, it is “hard to measure change” and difficult to make informed policy decisions. Funding for deaf-blind projects has also been frozen for many years, and several interviewees mentioned the need for increased funding in order to better serve children with DB in their states, particularly in those cases where the states have identified more children than they have resources to serve. One interviewee noted that it was irresponsible to continue to identify children with DB without then providing them with necessary services: “At some point, if we keep expending effort to define the population in a way that we know we can’t serve, what’s the point in that?” Other policy recommendations include:

- Ensure that educational professionals working with children with DB receive appropriate preservice and inservice training.
- Work to “close the gap” between OSEP Child Count and NTAC census figures.
- Continue to support DB projects through federal dollars, particularly the TA component of these projects.
- Maintain personnel preparation programs specific to DB at state or regional levels and promote distance education models.
- Provide appropriate follow-up services to young children who fail the NBHS and/or are identified with a syndrome that closely relates to DB.
- Use terminology such as dual sensory impairment instead of deaf-blindness to “broaden understanding” of the wide range of conditions included under this disability category.
- Create a more formalized system for sharing information across agencies, including those responsible for newborn hearing screening and newborn vision screening, enabling the state departments of education to track at-risk children.

¹⁵ Significantly, this would be accomplished through the NTAC revisions currently pending and to be implemented upon OSEP’s publication of final IDEA 2004 regulations.

- Share annual NTAC census figures, in addition to OSEP Child Count figures, with state and federal legislators, along with a brief explanation for the discrepancy.

Concluding Remarks

The 10 deaf-blind projects interviewed for this document reflect the tremendous diversity among deaf-blind projects. The interviews pointed out some of the common issues and concerns regarding the discrepancy between OSEP Child Count and NTAC census figures. A significant majority of interviewees agreed that this discrepancy in figures has a negative impact on the field as a whole, most importantly: fewer services available for children with DB, fewer opportunities for professional development at both the preservice and inservice levels, and insufficient research dollars. Although interviewees offered a number of conflicting policy recommendations, most agreed that getting an accurate count of children with DB remained a significant challenge and that closing the gap between OSEP Child Count and NTAC census figures was an important goal. Furthermore, directors of all projects seemed to agree that NTAC census figures (and not just OSEP Child Count figures) should be used to generate policy at both the state and federal levels, and that deaf-blind projects should receive increasing support for the unique contribution they make by providing TA to teachers of the DB and outreach to children with DB and their families.

This report was supported by the U.S. Department of Education (Cooperative Agreement No. H326F000001). However, the opinions expressed herein do not necessarily reflect the position of the U.S. Department of Education, and no official endorsement by the Department should be inferred.

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Appendix A Interview Protocol

The purpose of this study is to better understand issues faced by states related to identification of children and youth with deaf-blindness. According to the U.S. Department of Education's Office of Special Education Programs (OSEP), only 1,752 children ages 6-21 years and an additional 259 children ages 3-5 years were reported as having deaf-blindness during the 2004 academic year – for a total of 2,011 children.¹⁶ Figures collected via the DB Census using means of counting other than Child Count (which only counts students for whom deaf-blindness is identified as their “primary” disability), however, indicate that there are closer to 10,000 students throughout the nation with deaf-blindness. This profound discrepancy in identification has serious implications for – among other things – how funding is determined, services are provided, personnel preparation is conducted, and assessment is handled.

The following interview questions will be asked of 10 state's Deaf-Blind Project Coordinators.

- ❖ How is data gathered by the DB Project regarding numbers of children with deaf-blindness in your state (Probe: From whom and/or what sources does the DB Project solicit information – e.g., LEAs, Part C lead agencies, other agencies, newborn hearing screening data, information from hospitals for prematurely born)?
- ❖ What, if any, are the eligibility criteria for being included in the DB Census (e.g., functional evaluation as opposed to formal audiological assessment)?
- ❖ What are the primary obstacles in your state to collecting an accurate count of children and youth identified with deaf-blindness?

According to Child Count data, your state has [insert total] children identified with deaf-blindness. However, according to NTAC Census data, your state has [insert total] children identified with deaf-blindness.

- ❖ What accounts for this disparity in figures?
- ❖ What are the major policy/practice implications of this disparity in figures? (Probe for: funding, provision of services, personnel preparation, assessment, research, etc.)
- ❖ What policy recommendations would you make to ensure that identification issues are appropriately addressed and dealt with?

¹⁶ This information was downloaded on December 7, 2005 from www.ideadata.org.