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Research article

Expanding Our Understandings of Students who are Deaf-Blind by Exploring National Longitudinal Data

[Running Head: CHARACTERISTICS OF STUDENTS WHO ARE DEAF-BLIND]

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Abstract

This study adds to the body of literature examining characteristics of students who are deaf-blind including communication choices, educational placements, and academic accommodations of students in the Special Education Elementary Longitudinal Study (SEELS) funded by the United States Department of Education. The data presented in this study come from the first wave and represent information from parent interviews and teacher questionnaires. SPSS descriptive analysis was performed through frequencies and cross tabulations of selected variables in the SEELS data. Two sets of data are reported:deaf-blind primary (deaf-blind as the primary disability) anddual sensory combined (combination vision and hearing loss as a primary, secondary or tertiary disability).Percentages for both groupsare reported and compared to existing data in the areas of hearing loss, communication choice, educational placement, accommodations and parental expectations. The range of findings is diverse across both categories and when compared to existing data sources.

Keywords: deaf-blind, deafblind, dual sensory loss, SEELS, deaf-blindness

Introduction

Under Individuals with Disabilities Education Act (IDEA), deaf-blindness is a condition in which there is a combination of visual and hearing loss that could cause severe communication challenges and developmental and/or learning needs. Because of the particular challenges in these areas, students who are deaf-blind cannot typically be accommodated in programs exclusively for children with visual impairments, hearing loss, or severe disabilities. To be considered deaf-blind, a student must be identified with bothavision and a hearing loss. There are different combinations of the disability: totally blind and profoundly deaf, low vision and hearing loss, totally blind and hearing loss, or low vision and profoundly deaf. Furthermore, Everson (1995) described four categories of deaf-blindness: (a) congenital deaf-blindness, (b) adventitious deaf-blindness, (c) congenital deafness-adventitious blindness, and (d) congenital blindness-adventitious deafness. The age of onset and degree and progression of the dual sensory losses are critical factors that could impact the learning experiences of students with deaf-blindness.

The heterogeneity within this group, coupled with the high percentage of children who are deaf-blind and who have an additional disability, has made the reporting of these children a difficult task. Although the federal definition is used by all federal reporting agencies, the counts differ every year which has led to an underrepresentation of students who are deaf-blind. Herbster (2015) reviewed data from the two federal reporting sources:The National Deaf-Blind Center (NCDB) and The December 1 Special Education Child Count. When these numbers were compared, there was a major discrepancy of nearly 8,000 children reported with deaf-blindness between the two counts. NCDBreported 9,525 compared to 1,587 for the December 1 Special Education Child Count(Herbster, 2015). It has been suggested that because many of the students with deaf-blindness have an additional disability, most schools report this as multiple disability rather than deaf-blind (Muller, 2006). Herbster (2015) also states that although a definition of deaf-blindness is provided in federal law, “states have some discretion as to how the exact terminology within the definition is utilized” (p. 6)including dual-sensory impaired, dual disability, and multi-handicapped.

The unique needs of this heterogeneous group of students make it complex to design and implement an efficient educational program. Because of the particular challenges in these areas, students who are deaf-blind cannot typically be educated in programs exclusively for children with visual impairments, hearing loss, or severe disabilities. Over the last several years, the educational settings in the U.S.where students with deaf-blindness are

being educated have changed from more segregated settings such as institution-based services and self-contained classrooms to mainstreaming and inclusion in general education settings. The most recent National Child Count of Children and Youth who are Deaf-Blind (2016) reports that just over 61% of school-aged children are in the general education classroom for at least a portion of the day (NCDB, 2016). Similarly, The Office of Special Education Programs (OSEP) in its *37th Annual Report to Congress on the Implementation of IDEA* (2015) reported educational environments for students with deaf-blindness as 23.6% (80% or more the day in general education settings); 12% (40-79% of the day); 34.9% (less than 40% of the day); and 29.5% in "other environments".

Empirical data on communication and language with children who are deaf-blind is scarce (Vervloed, Van Dijk, Knoors, & Van Dijk, 2006). Chen (2004) acknowledged that, "the child's communication mode and skills will depend on the type and degree of visual impairment and hearing loss, the age of onset, and whether the child has additional disabilities" (p. 278). Students identified with deaf-blindness exhibit a range of hearing loss from mild to profound and vision loss from low vision to total blindness. Depending on the type and degree of hearing loss, a student with deaf-blindness may use a variety of amplification options including personal hearing aids, assistive listening devices, or cochlear implants. While limited data exist documenting the effectiveness of these amplification options, some data is beginning to emerge on the use of cochlear implants with the deaf-blind population (Bashinski, Durando, & Thomas, 2010; NCDB, 2012; Stremel, 2009).

When the vision and hearing of a child are both limited, the natural opportunities for social interactions, communication, and learning can be severely impacted (Correa-Torres, 2008). Students who have deaf-blindness may experience distinctive challenges when accessing the core curriculum in classrooms, including access to print material, access to visual and/or audio presentation, communication with adults and peers, and incidental learning, among others.

Oftentimes, teachers are not trained in the area of deaf-blindness and do not have the necessary skills to identify and/or support the needs of these students (Correa-Torres, Bowen &Furze, 2016; Corn & Ferrell, 2000; Hartmann, 2012).As a result, the unique needs of students who are deaf-blind may not always be met or addressed. In order to understand these unique needs and suggest skills and knowledge teachers may need, this study aimed to examine data on the communication choices, educational placements, and academic accommodations of students who are deaf-blind as reported in the Special Education Elementary Longitudinal Study (SEELS).

Materials and Method

SEELS Data Set

The data presented in this study come from the Special Education Elementary Longitudinal Study (SEELS). SEELS was funded by the U.S. Department of Education, Office of Special Education Programs (OSEP). SEELS documented the school experiences of a national sample of students as they moved from elementary to middle school and from middle to high school. The students ranged in age from 6-13 at the onset of the study. The sample included more than 11,000 students from all disability categories, including students with deaf-blindness. SEELS was designed to assess change in students' educational, social, vocational, and personal development over time. Data were collected at three points in time through school staff, direct assessments, and parent interviews. The data presented in this study come from the first wave and represent information from parent interviews and teacher questionnaires.

The deaf-blind population has the lowest incidence of occurrence among all of the low incidence disabilities. Because of the low numbers of identified students, it is difficult to obtain a large sample of children and youth with deaf-blindness for research purposes. The SEELS data allow researchers to examine large populations of students with various disabilities and thousands of demographic and academic variables; see for example Banerjee, Sundeen, Hutchinson, & Jackson, 2016; Bowman-Perrott, Benz, Hsu, Kwok, Eisterhold, & Zhang, 2013; Duchnowski, Kutash, Green, Ferron, Wagner, &Vengrofski, 2013; and Ju, Zhang, &Katsiyannis, 2013. Only a few studies have analyzed the SEELS data related to vision loss (Kelly & Smith, 2008; Kelly, 2009; Kelly, 2011) and only one related to hearing loss (Wilkens, 2009). None to date have focused on students who are deaf-blind. Based on the unique needs of students who are deaf-blind and the vast range of characteristics associated with this group of children, this study, will add to the existing knowledge base by examining data on the communication choices, educational placements, access to curriculum, and academic accommodations of students who are deaf-blind as reported in the SEELS.

Participants

Participants in the SEELS were asked to identify the student's primary disability and any additional or concomitant disabilities that impacted the student's educational needs. Parent-reported data identified 49 students as deaf-blind. The primary indicator of deaf-blindness was present for each student throughout each section of the data

and the ensuing analyses collected by SEELS. Parents were also asked to identify if a child had a secondary or other disability. From this data, additional SEELSstudents were identified as having a primary disability of deafness or hearing impairment[1] with a secondary disability of blindness or visual impairment[2] and vice versa. Based on parent report of having either a hearing loss or vision loss as the primary and the other as the secondary and/or tertiary disability, 124 additional students in the data were identified as having some degree of dual sensory loss. For the purpose of examining students who also had hearing and vision loss beyond the primary indicator of deaf-blindness, we selected students that reported any combination of a visual impairment and hearing impairment. The combinations of visual impairment and hearing impairment were generated from both the primary disability indicator and family-reported multiple response indicators that were sampled from the parents of each student. In this analysis, data for the primary deaf-blind group is presented individually and data for the additional students is presented separately in this study under the title of Dual Sensory combined. Table 1 identifies the primary disability for the students in the dual sensory combined category.

Data Analysis

For the purpose of this analysis, SPSS version 19.0 was used for all data procedures. Descriptive analysis was preformed through frequencies and cross tabulations of selected variables and is the primary source for interpretation of the data. Two sets of data are reported for this analysis: *deaf-blind primary* and *dual sensory combined)*. DB primary refers directly to students who were reported as having deaf-blind as their primary disability. Dual sensory combined reports on students with a combination vision and hearing loss as a primary, secondary or tertiary disability.

Unique Cluster Sampling Considerations

Large secondary data sets provide opportunities to examine individual variables that otherwise may not be available to a researcher. SEELS data were collected nationally to represent students in special education throughout the United States. Local education agencies (LEAs) and state operated schools for the deaf and blind participated in the study. It is important to note that SEELS used stratified special education rosters to ensure that identification of individual students would not be reported and selected a percentage of students from each disability category. However,"from the state-supported special schools, 100% of students with deaf-blindness …were sampled" (SEELS, 2004, p. 4). This type of sampling poses a problem with statistical measures that assume a random sample

of participants (Hahs-Vaughn, 2006). Because of this situation, two considerations must be taken into account when analyzing SEELS data. First, consideration must be given to the stratified sample of the schools in the sample and second, to the clusters of students within each school particularly of students with deaf-blindness.

To address these considerations, SEELS provided sample weights for each participant based on the sampling location and the particular disability. Specifically, "for the state schools, the number of students in each disability category was estimated by multiplying the number of students with that disability on the rosters by the inverse of the proportion of state schools that submitted rosters" (SEELS, 2004, p. 8). Because larger weights were assigned to more uncommon disabilities, students with deaf-blindness may be over-sampled within the data. This was purposefully done to attempt to better represent the overall population of students in each category. Understanding this type of sampling and the weights applied is critical for analysis and reporting of the data. Raw weights provided by SEELS represent the total population of special education students across the United States. These weights are appropriate to use for descriptive analysis of the data. For a detailed analysis of SEELS sampling, data collection, and analysis procedures please review the documents provided by SEELS at the official website (www.SEELS.net).

Results and Discussion

The level of hearing loss often dictates the type of amplification used. This in turn informs the communication choices available for a student. In order to look at the communication choices for the students in this study, the level of hearing loss was documented as reported by the parents. Access to individual audiometric information was not available. The parents in the SEELS were only given three categories from which to choose: mild, moderate or profound. Participants in the deaf-blind category had a more varied range of hearing loss than those from the dual sensory combined group. However, the percentages suggest that hearing loss is not as severe in the dual sensory combined category and may explain why students are not classified as deaf-blind. The data also show that both groups in the SEELS data had a higher incidence of mild loss than the general population and a similar incidence of profound loss with the DB primary group, but much lower in the dual sensory combined group. With the wide variation of reporting in the moderate level, it is difficult to make any comparisons. To better understand the implications of the hearing loss in this population, the information from the SEELS was compared to the Gallaudet Research Institute (GRI). GRI collects data annually on students who are deaf or hard of hearing

throughout the United States to show trends in the school age population. Table 2 compares the range of degree of hearing loss reported for the SEELS participants with the range of hearing loss reported by GRI during the same reporting time (GRI, 2002).

DB primary participants in the SEELS data wore hearing aids 85% of the time as compared with only 23.1% of the dual sensory combined participants. Only 1% of the DB primary group reported the child had received a cochlear implant, while 3% of the dual sensory combined group reported receiving a cochlear implant. To compare this with the population of students with only hearing loss, 62.9% of the GRI population used a hearing aid for instruction and 6.2% had a cochlear implant. The higher proportion of hearing aid users in the SEELS data may be reflective of the higher incidence of mild hearing loss.

Communication choice was provided by parent respondents in the SEELS data. Although parents were given a selection of choices, not all communication systems were presented. However, we can still look at the trends. Table 3 provides a summary of the communication choices reported. Oral spoken language was used by the majority of students in both groups. Sign language was used more often by the DB primary category than dual sensory combined. This indicates that many of the students used a combination of spoken and signed language. What we are unable to glean from the data is the type of sign language used (i.e., ASL, Signed English, PSE,etc.) or the level of proficiency in the communication mode, either spoken or signed. It is also important to note the use of alternative communication choices largely by the students with deaf-blind as their primary disability. When we compare this information with the data collected by GRI (2002), we see comparable trends. GRI reports language or modality used in the primary method of teaching for students rather than the primary method of communication. However, we can see that 45.4% reported using speech only, 46.9% used sign and speech combined, and 6.3% used sign only.

Data related to the type of school the child attended were reported both by the parent and by the administrative staff at each school where data were collected. Regular schools[3]weredescribed as general education settings in public neighborhood schools. Residential Schools for the Deaf or the Blind were defined as special schools. The majority of students in both categories attended the regular school(80.6 % DB primary and 93.9% dual sensory combined). This information is concurrent with previous reports that the number of students with deaf-blindness being educated in general education classrooms is continually increasing and although some segregation

still exists, inclusion has given children who are deaf-blind the opportunity to be educated and socialized with their nondisabled peers (Correa-Torres, 2008).

SEELS participants received several accommodations and supports. When reviewing the information on how students' learning and progress was measured, results indicated that over 45% of participants received testing accommodations (45.8% for DB primary and 65.7% for dual sensory combined), over 41% received alternative tests (59.25 for DB primary and 41.1% for dual sensory combined), and over 34% had modified grade standards (34.2% for DB primary and 34.3% for dual sensory combined). Also, the majority of participants in both groups received instructional accommodations (76.5% DB primary and 65.4 dual sensory combined). However, when looking at the "physical adaptations" SEELS category, more students under the DB primary category received this accommodation than students under the dual sensory combined category (78% versus 43.5%). The percentage of participants using supports was much higher for students who were identified as having deaf-blindness as their primary disability. The only area of support in which the proportion was higher for the dual sensory combined group was tutor support (14.5% DB primary and 18.1% dual sensory combined).

The purpose of this study was to examine data on the communication choices, educational placements, and academic accommodationsof students who are deaf-blind as reported in the Special Education Elementary Longitudinal Study (SEELS) to add to the existing body of literature and understand the educational needs of these students. Overall, this study found several key outcomes that have important implications for professionals working with students who have deaf-blindness. First and foremost is the understanding and working definition of students who qualify for services under the IDEA deaf-blind category. The range of deaf-blindness is vast. Some have usable vision or hearing, while others are more limited. The 2015 National Child Count (2016) reported,

> The broad ranges and combinations of vision and hearing loss of the children and youth on the National Deaf-Blind Child Count provide evidence of the heterogeneous nature of this population and their needs. Only about 1% of the population has a profound hearing loss and is totally blind. The other 99% have some residual hearing or vision. (Section Documented Hearing and Vision Loss, para. 9).

This range of abilities, along with the high percentage of deaf-blind children who have an additional disability, has made the reporting of these children a difficult task. The discrepancy in reporting has been demonstrated through the National Center of Deaf-Blindness and the OSEP child counts. This discrepancy has an

impact not only on funding, but also on policy and delivery of services for these students (Herbster, 2015). We identified 49 children in the SEELS data under the primary disability category of deaf-blind. However, an additional 124 students were identified with having a variety of "other" disabilities in addition to combined hearing and vision loss. The 2015 National Child Count of Children and Youth who are Deaf-Blind (2016) reports thatoverall, the number of childrenor youth with additional disabilities is increasing. In 2005,over 20% of the children/youth on the Deaf-Blind Child Count had no additionaldisabilities. However, in 2015, 90% reported at least one additional disability with 44% reporting four or more additional disabilities.

Secondly, we expected students in the dual sensory combined category to have more needs compared to the students in the DB primary category. However, the results across all areas provided a greater range than expected. This may be indicative of the varying types of additional disabilities from all disability categories (see Table 1). This finding has important implications for educational programming to ensure that students' individual academic and social needs are met.

Similar to other children and youth with hearing loss, the child with deaf-blindness may use spoken language, sign language or a combination of both. However, communication for some students who are deaf-blind may also include using behavior cues to express wants and needs. In addition, "many children who are deaf-blind may need alternative means to support their communication, such as the use of object cues, other tangible symbols… particularly if they have additional disabilities" (Chen, 2004, p. 278). Nevertheless, identifying effective communication tools for children who are deaf-blind may be a difficult task as many of the augmentative tools and strategies currently used require either intact vision or intact audition to be effective.

Finally, the number of students who are deaf-blind receiving a cochlear implant is increasing. The 2015 National Child Count of Children and Youth who are Deaf-Blind (2016) identified the number of children with deaf-blindness who had received a cochlear implant hadincreased from 167 in 2005 to 1,085 in 2015. These results indicate that we could expect to see an increase in the number of children with deaf-blindness being considered for cochlear implants in the future. However, as Stremel and Malloy (2006) have cautioned "research to determine the effectiveness of cochlear implants for these children is limited" (p. 3). It is critical that professionals are trained to provide appropriate interventions to allow students to maximize cochlear implant use to the fullest potential possible since there is a paucity of research examining the effectiveness of cochlear implants for these children.

Conclusion

Implications for Practitioners

The challenges professionals who work with students who are deaf-blind experience are not only evident on the provision of services, but also when correctly identifying these students. When comparing the data reported by OSEP and NCDB, the discrepancy between the two numbers is obvious. The heterogeneous nature and the diverse characteristics of this disability often result in misidentification of students who are deaf-blind, particularly when they are classified under different disability categories such as multiple disabilities. This not only has an impact on the child count, but also on the provision of appropriate services for these students. Students with dual sensory disabilities often cannot be educated in programs solely for children with vision, hearing loss or severe disabilities. Because communication is one of the areas most impacted by this disability, students who are deaf-blind should be educated in programs where there are supports to address their specific and unique needs. If students are not identified correctly, the provision of appropriate services may be compromised. The 2013 NCDB report indicates that there "areincreased needs for more interventionists and teachers with a knowledge of deaf-blind intervention and instruction, as well as individualized supports" (NCDB, 2014, p. 5).

Implications for University Preparation Programs

One way to address the issue of misidentification and better educational practices for students who are deaf-blind could be by addressing university personnel preparation programs. Currently, there are few programs that prepare personnel to work exclusively with this population. Increasing the number of programs, teaching certificates or professional development in this area would be ideal. In addition, it would be beneficial if programs that prepare teachers of students with visual impairments and teachers of the deaf addressed the education of students who are deaf-blind more in-depth in their courses (Correa-Torres, Bowen &Furze, 2016). As reported by Chen (2004), university programs that prepare teachers of the deaf rarely address the topic of deaf-blindness in their courses, and when they do, it usually only covers the surface (introduction or awareness) about the topic. Although in programs that prepare teachers of students with visually impairments the topic of deaf-blindness is approached or talked about more, it has been reported that the knowledge these teachers have when they graduate with their degree is minimal and not enough to know what to do with students with this disability on their caseload (Bruce, 2007). Both programs should include more information not only on how to better address the academic needs of these students, but also

how to better identify students with dual sensory disabilities, as well as show the future teacher of the deaf and teacher of the visually impaired how to effectively collaborate with one another to identify appropriate goals for these students. This collaboration is critical to involve professionals from across disciplines to ensure that services for students with deaf-blindness are being met. Chen (2004) reiterated, "whatever the type of learning environment, the educational program for a young child who is deaf-blind must address the child's abilities, visual impairment, hearing loss, and other special needs, and involve a team of professionals from these disciplines" (p. 282). If this type of collaboration is not included in teacher preparation programs, professional development opportunities for professionals who are already working in the field would be beneficial.

Limitations

Deaf-blindness is considered a low incidence disability, and among this category, one with the lowest number of students identified. Because of this, studies that contain a large number of participants are uncommon. Having a large data set from a national sample, like SEELS, provided the opportunity to access participants and information that otherwise would have been impossible to study. However, there were some limitations when analyzing the data. The fact that others collected the data and the lack of control over what data were collected proved to be a challenge when looking at variables and during the analysis process. At times, the authors had questions about the data that were inexplicable because of the study methods or because documentation was not available.

Second, while the US federal definition of deaf-blindness seems straightforward, schools vary in the way students are reported. Very little guidance was given to parents or educators to assist them in identifying the primary disability category for the SEELS participants. Marder (2009) explained:

> The [SEELS] instructions did not specify what information respondents were to use in answering the questions. Thus, some respondents may have consulted students' IEPs, whereas others may have used their own subjective judgment. In addition, for some students with more than one disability, identification of which disability was primary may not have been clear cut (p. 2).

Therefore, the actual count for students in this category may vary depending on additional disabilities and theparent's perception of the severity of either the hearing loss or the vision loss.

Notwithstanding these limitations, the findings presented in this study add to the body of research and knowledge of practice for students who are deaf-blind. As a group, these children and youth demonstrate a wide range of variability in their hearing and vision loss, their communication access and method of communication, their amplification choices, and their additional disability needs. It is concerning, but not surprising, that professionals choose the category of multiple disabilities rather than deaf-blind resulting in an ineffective educational program with service providers who are unfamiliar with strategies and educational practices for students who are deaf-blind. One solution to remedy this problem is to provide more comprehensive educational options at the university level and targeted professional development at the school and district level. The ultimate goal is to provide a quality education to children and youth who are deaf-blind.

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Tables

Table 1. Dual sensory combined Primary Disability Reported in the SEELS Study

Primary Disability	**N**
Learning Disability	4
Speech Impairment	1
Mental Retardation	3
Hearing Impairment	44
Visual Impairment	37
Orthopedic Impairment	6
Other Health Impairment	5
Autism	3
Traumatic Brain Injury	3
Multiple Disabilities	18
Total	124

Table 2. Degree of Hearing Loss Reported by GRI compared with Degree of Hearing Loss Reported by SEELS

Degree of Hearing Loss	GRI Percentage	SEELS DB Primary	SEELS DB Combined
Mild (27-40 dB, ANSI)	11.3	25.9%	53.0%
Moderate (41-55 dB, ANSI)	12.8	40.2%	30.8%
Moderate-Severe (56-70 dB, ANSI)	12.3	NR	NR
Severe (71-90 dB, ANSI)	15.8	NR	NR
Profound (91 dB & above, ANSI)	32.2	33.9%	16.2%

Table 3. Communication Choice Reported for SEELS Participants

	DB Primary	DualSensory Combined
Sign language	58.3%	20.1%
Oral speech	69.7%	78.6%
Communication board/book	32.7%	6.8%

Endnotes

1. [1]SEELS uses the terms hearing impairment and deafness as two distinct coding options, depending on the severity of loss
2. [2]SEELS uses the terms visual impairment and blindness as two distinct coding options, depending on the severity of loss
3. [3]Terminology consistent with the SEELS data is used to report educational settings (e.g. regular school and special school).