Special Education Eligibility and the Category of Deafblindness: Examining the Perspectives of Case Coordinators

Dissertation

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Abstract

Research in the field of deafblindness has shown that the population is a very heterogeneous group with varying degrees of loss related to vision and hearing, and most often times the presence of additional disabilities, which can lead to an underrepresentation of children who have the disability. A review of 2012 data from two federal reporting sources, including the National Child Count of Children and Youth who are Deafblind, through the National Center on Deafblindness (NCDB), show the number of children with deafblindness, ages three through twenty-one years, across the nation to total 9,525 (NCDB, 2014), Conversely, national data reported for children with a combination of vision and hearing loss reported through state educational agencies nationwide as part of the December 1 Special Education Child Count total 1,587. This major discrepancy between data sources regarding the same disability category (e.g., deafblindness) being reported federally indicates a need to better understand the evaluation process for children at the local school district level.

The field of deafblindness has limited research in the area of identification and those small-scale studies that exist indicate a tendency for researchers to use similar participant pools (e.g., deafblind project staff) to speculate as to why school personnel report children with vision and hearing losses as having disabilities other than deafblindness. Although these individuals can play a key role as active members of an
educational team, they may or may not be part of an initial evaluation for a child as part of the process to determine the classification of deafblindness, as would other professionals such as special education coordinators and school psychologists (e.g., case coordinators).

As facilitators of service delivery and as trained evaluators, case coordinators play a crucial and consistent role in the evaluation process for children across disability groups. For this reason, a qualitative study with these professionals was proposed with the use of multiple data sources to gather and analyze information regarding the evaluation process to gain a greater understanding of the factors that dictate decision-making for children who are deafblind. Participants were randomly selected from groups oriented by district typology that have reported having children with deafblindness using child count data reported to the department of education in one state for 2012. As an exploratory study being guided by the principles of grounded theory the intended result was to generate theory around factors that influence the process of identification for children who are deafblind to begin contextualizing the issue of underidentification. The following research question was addressed:

From the perspective of case coordinators (e.g., special education coordinators, school psychologists) what factors (e.g., medical, educational, social) influence the identification process for children who are deafblind?
Dedication

Dedicated to the memory of my father, Fred Phillips, who explored new ideas with fervor, never doubted the potential in people, and recognized opportunity in every aspect of life. You are greatly missed.
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First and foremost I want to thank my parents for presenting me with a range of experiences that shaped my interests in life very early on. Without those opportunities and their support along the way, I would have never believed that I could take on so many of the challenges that life has to offer.

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My appreciation extends to the guidance and mentorship offered by the candidacy and dissertation committees that worked closely with me during my time as a student including my advisor, Dr. Peter Paul, in addition to Drs. Laurice Joseph, Diane Sainato, Colette Dollarhide and Dorinda Gallant. Your time and effort through
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Everyday I am thankful for my children, Reagan, Sydney and Grant, who have no memory of a time when I haven’t been in school and I thank them more than anything for their youthful spirits, caring natures and unconscious abilities to keep me grounded better than anyone else can. Their wonder inspires and reminds me daily of the importance of quality education for all young minds and our responsibilities as adults to nurture that development.

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Vita

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Field of Study

Major Field: Education
Table of Contents

Abstract ............................................................................................................ ii
Dedication ......................................................................................................... iv
Acknowledgements .......................................................................................... v
Vita .................................................................................................................... vii
List of Tables .................................................................................................... xii
List of Figures ................................................................................................... xiii

Chapters:

Chapter 1: Introduction .................................................................................. 1

    Purpose of this Study .................................................................................. 3
    Rationale for the Study .............................................................................. 4
    Research Question ..................................................................................... 10
    Significance of the Study ............................................................................ 10

Chapter 2: Literature Review ......................................................................... 13

    Introduction .................................................................................................. 13
    Identification in Disabilities Other Than Deafblindness ......................... 13
        Visual Impairment Including Blindness ................................................ 14
        Hearing Impairment Including Deafness .............................................. 15
        Intellectual Disability (Mental Retardation until 2010) ....................... 18
Autism.................................................................19

Emotional Disturbance............................................21

Identification in Deafblindness...............................22

Guidance from the Law.........................................23

Collecting the Data.............................................27

Evaluating the Child............................................29

Considerations for Improving the Child Count Process........32

Suggested Research............................................33

Chapter 3: Methodology.......................................36

Introduction..................................................36

Participants..................................................37

Methods.....................................................41

Analysis.....................................................45

Trustworthiness.............................................49

Chapter 4: Findings............................................52

Introduction................................................52

Factor One: Previous Records..............................55

Theme: Medical.............................................55

Theme: Prior District/Program.........................57

Theme: Parent/Family....................................58

Factor Two: Data..........................................59

Theme: Response to Intervention......................59
## List of Tables

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.1 National Child Count of Children and Youth who are Deafblind-Snap Snap Shot Number</td>
<td>23</td>
</tr>
<tr>
<td>2.2 National Child Count Data Compared to Federal Child Count for Ohio Over the Last Five Reporting Cycles for Children Ages 3-21</td>
<td>28</td>
</tr>
<tr>
<td>2.3 National Child Count Data Compared to Federal Child Count for California Over the Last Five Reporting Cycles for Children Ages 3-21</td>
<td>29</td>
</tr>
<tr>
<td>3.1 Description of Major District Typology Groupings</td>
<td>38</td>
</tr>
<tr>
<td>3.2 District Typology Totals for Children Reported as Having Deafblindness in 2012-13</td>
<td>39</td>
</tr>
<tr>
<td>3.3 Study Timeline for 2014-15 Illustrating Staggered Approach for Districts</td>
<td>40</td>
</tr>
<tr>
<td>3.4 Scientific and Naturalistic Terms Appropriate to the Four Aspects of Trustworthiness</td>
<td>50</td>
</tr>
<tr>
<td>4.1 District Participants Demographics</td>
<td>53</td>
</tr>
</tbody>
</table>
## List of Figures

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.1 Prominent Factors in the Identification Process from the Perspective of Case Coordinators</td>
<td>54</td>
</tr>
<tr>
<td>4.2 Factor Prominence Across the Stages of Identification</td>
<td>80</td>
</tr>
<tr>
<td>4.3 Relationships Between Factors with the Stages of the Identification Process in Rural Settings</td>
<td>81</td>
</tr>
<tr>
<td>4.4 Relationships Between Factors with the Stages of the Identification Process in Urban Settings</td>
<td>82</td>
</tr>
<tr>
<td>4.5 Relationships Between Factors with the Stages of the Identification Process in Suburban Settings</td>
<td>82</td>
</tr>
<tr>
<td>4.6 Relationships Between Factors with the Stages of the Identification Process in Small Town Settings</td>
<td>83</td>
</tr>
</tbody>
</table>
Chapter 1: Introduction

For children with disabilities, the road to equal access for educational opportunities has stretched out over the last four decades. Prior to the early seventies, education for students with disabilities was not mandated by law leaving many without opportunities to formally learn among their peers. Institutionalization was not uncommon for many with no supports being provided that would allow for connection with mainstream society or families. Over time we have seen changes that have been enacted by federal and state government to create what would be termed a free and appropriate public education (FAPE). As Keogh (2007) states, it is important to remember that many of these changes in educational policies and practices came about because students with disabilities and their families exercised their civil rights by demanding an equal educational experience.

One challenge in this pursuit of a more equitable education begins with the notion of child find and the determination of a disability. As many states employ a categorical system in regards to the practice of special education, a child must first be evaluated to initiate more individualized educational supports so that they may participate fully in the classroom. These evaluations lead to the identification of children as having a specific disability and inclusion in the state and federal child count data reporting, which is annually collected for tracking purposes.
Federal mandates for the collection of child count data began with the passing of Public Law 94-142, which is known today at the Individuals with Disabilities Act (IDEA). Child count totals are reported each year by states and include all children ages three to twenty-one identified with disabilities. These data represent children and impact educational policy, funding and service. Eligibility for special education services and supports is initiated by the identification of students as having a disability that falls into one of fourteen categories including: autism, deafblindness, deafness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairment, specific learning disability, speech or language impairment, traumatic brain injury, and visual impairment, including blindness.

The categorical system that is currently in place to support the needs of children has been criticized for the possible under/overrepresentation of students in one category versus another. For the purposes of this study, a focus will be placed on representation in the category of deafblindness. Existing research in the field of deafblindness has shown that the population is a heterogeneous group with varying degrees of loss related to vision and hearing, which can lead to an underrepresentation of children who have the disability. This raises one of many concerns related to the screening and evaluation processes for children who are deafblind that lead to the establishment of educational services and supports.

To bridge gaps and provide equitable service, identifying a child’s level of vision and hearing as early as possible is imperative for provision of appropriate interventions. Children who are deafblind require such interventions in the areas of both vision and
hearing to establish meaningful connections in the world. For families and service providers of children with sensory loss understanding how to help children make that connection is often not something that they have experienced. It is common for parents to rely heavily on the knowledge of others, including family members, early intervention service providers and specialized educational personnel, to take steps forward to understand how to communicate with and teach their children.

My interest in the area of evaluation for children who are deafblind is primary linked to the function of eligibility determination for the disability. Currently, child identification research in the deafblind field shows drastically different counts for children reported under the state educational agency data that is part of the Federal Child Count, and the National Child Count for Children and Youth who are Deafblind reported by state deafblind projects, which are both reported to the Office for Special Education Programs (OSEP) as part of the U.S. Department of Education.

**Purpose of this study**

The purpose of this exploratory study was to utilize a qualitative research methodology for developing theory associated with the identification of children who are deafblind. Through onsite interviews, guided by the principles of grounded theory with district case coordinators (e.g., special education directors, school psychologists) an examination of the process for determining the disability classification for children was completed. In an attempt to gain a better understanding of the perspectives of these individuals, interviews were completed in nine districts to collect data related to the evaluation and eligibility process. These districts represented urban, small town, suburban and rural areas. The application of constant comparative methods utilizing a
team of research consultants dictated how elements from the data were grouped and contextualized to formulate theory related to service provision.

**Rationale for the study**

A federal definition for *deafblindness* was established to accurately identify children with a combination of vision and hearing loss and highlight their unique educational needs. The *Individuals with Disabilities Education Act* defines deafblindness as:

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 CRF 300.8 (c) (2)].

Both the Federal Child Count and National Child Count rely upon this definition to identify deafblind children and categorize the demographic for the respective reporting requirements. That being said, these counts differ substantially every year. The necessity for an additional count is evidenced through a comparison from the 2012 data from both counts which reflects a total number of children, ages three through twenty-one, as 9,525 through the National Count of Children and Youth who are Deafblind (NCC) versus the 1,587 children identified through the WESTAT data or Federal Child Count (FCC) used by OSEP (NCDB, 2014). These inconsistencies over time have caused some researchers to ask why. The lack of research in the area has not led to any clear conclusions.

Determining the number of children who are deafblind has been a struggle since the creation of the category of “deafblindness” in the late 1960’s following the Rubella epidemic. The spectrum of vision and hearing losses makes an extremely heterogeneous, low-incidence population that is challenging to research, assess and serve. Markowitz
(2001) acknowledged that providing a free and appropriate public education for students with deafblindness presents challenges for practitioners and administrators around the country. Deafblindness is an unclear concept, most frequently referring not to a total absence of hearing and vision, but to some reduction in the body function of hearing and vision. (Danermark & Moller, 2007)

There are basically two sources of information that the federal government has access to that yield an aggregate count of these children (Baldwin, 1992). The state educational agencies are charged by federal law to maintain a count of all children, or FCC, within the districts of the state. Additionally, the U.S. Department of Education funds deafblind projects in every state, U.S. territories, the Virgin Islands and Puerto Rico to meet the unique needs of children with vision and hearing loss. These centers are responsible for maintaining a state count of children who are deafblind that is then reported to the National Center on Deaf-Blindness that maintains the NCC. Since the inception of the NCC, a large discrepancy between the both counts has existed. To identify causes for the large differences in numbers, Muller (2006) proposes that because the majority of children with deafblindness do have other disabilities as well, most are included in the FCC as having multiple disabilities as opposed to having deafblindness.

This definition goes beyond using disability-specific terminology in some states, where local school districts are provided supplemental funding for children based on their disability. In one midwestern state, this supplemental funding is represented in six weighted categories of which students with deafblindness, autism and/or traumatic brain injury receive the greatest amount. So consequently, a child whose primary disability is not reported through the state child count as having deafblindness may not be receiving
the appropriate amount of supplemental weighted funding to support their unique educational needs.

Challenges to properly identifying children who are deafblind are not limited to the range of vision and hearing losses, but also in the term *deafblindness* itself. Research in the field of deafblindness reflects inconsistencies regarding terms and definitions for *deafblindness*. Terms such as *multi-handicapped, deafblind, dual-sensory impaired, deaf/blind* and *dual disability* are just some examples used to identify the child who has a combination vision and hearing loss. In addition, none of the terms listed are a part of the federal definition of *deafblindness*, which is the only standard available to state education agencies and state deafblind projects to appropriately identify children through the child counts. It should be mentioned that although a federal definition is offered through the language of the law, states have some discretion as to how the exact terminology within the definition is utilized.

Riggio (1992) acknowledged that under the mandate of Public Law 94-142, children are entitled to a free and appropriate public education. As part of this education, they are also entitled to appropriate diagnostic testing in order to develop their educational plans. This testing is what leads to identification of a disability and the development of a plan for appropriate services and supports.

Kirchner and Diament (1999) state that it seems also to be the case that, for persons with a reduction in the function of vision and hearing, the sense first diagnosed, or that is most seriously limited, draws the most attention and not that the combination of hearing and vision loss that has the most implications for activity...
and participation. That overshadowing of the dual sensory loss often causes barriers for connection with the environment and the development of conceptual meaning.

Baldwin (1992) researched members of various state educational agencies to identify reasons why children who are deafblind were being incorrectly reported as having *multiple disabilities* on the FCC. The state administrators did not argue that these children were not deafblind, or did not have dual-sensory losses, but that they, or the school district had chosen to count them under the category of *multiple disabilities* (MD). Quite simply, in many cases these children were in classrooms for multi-disabled students and, therefore, were categorized in a similar manner. Historically, many teachers in these environments have not completed licensure requirements in the areas of visual and/or hearing impairments, which makes it challenging to understand the impact of instruction. Also, some administrators voiced the thought that, if they used the label of *Deafblindness*, their programs could be found in noncompliance since they had no specific programs or teachers who had training with children who were deafblind.

Kirchner and Diament (1999) also demonstrated that students with deafblindness run the risk of failing to receive the support they need because their unique vision and hearing needs are not accurately detected. This finding indicates the role of an adequate level of knowledge of deafblindness among persons in the student's immediate educational environment. Muller (2006) concluded that concerns about the under identification of deafblindness 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 development. Ideally, once a child is identified as having a specific disability, necessary services are determined to
provide intervention with specialists trained to meet the needs of the child as early in development as possible. Research has shown that often children who are deafblind do not receive comprehensive services. In some situations, as stated, reasons given for the lack of services from school administrators have been due to the lack of trained personnel and lack of funds. This is unacceptable by state and federal standards.

Edelman, Giangreco and Nelson (1998) acknowledge that the contribution of a hearing and/or vision specialist on the educational team can be important if the person is properly trained to meet the needs of a child with a combined sensory loss. Due to the tendency toward isolation for students who are deafblind because of the impact of the combined vision and hearing loss and the challenges it presents to make meaning, when students are not engaged by the outside world, professionals with experience and training in the impact of the combined loss are vital to addressing visual and hearing needs simultaneously giving the student a clearer picture of the world around them.

In a study of students with different types and degrees of disability, Erickson and Granlund (2004) studied students with disabilities and their levels of participation and concluded that the student's conception of participation typically did not depend on the type of disability, with one exception: the deafblind student. These students with limited or no level of vision and/or hearing remain isolated and lack access to activities among their peers.

In the discussion of funding, it should be noted that deafblind projects, which provide necessary support to local educational agencies by providing training in deafblindness to teachers and service providers, have been flat funded for a number of years. State educational agencies often provide supplemental funding to these projects so
that it can be reported at a federal level that the deafblind student’s needs are being addressed. Would accurate reporting of the FCC lead to increased funding on a federal level to deafblind projects for technical assistance? Since the Congress of the United States categorically funds deafblind projects, these discrepant reports cause Congressional concerns about the actual numbers of children. (Fredericks & Baldwin, 1987).

Federal regulations have emphasized the importance of deafblind projects and local educational agencies to provide evidence-based practice for intervention. Ronnberg and Borg (2001) concluded that the lack of evidenced-based research in the field of deafblindness is due to the heterogeneity in the low-incidence population, methodology required by experimental designs that limits results, and scientific obstacles of studies for meeting the standard of evidenced-based. More recently Ferrell, Bruce and Luckner (2014) reviewed the state of evidence-based practice in the field using a rubric and found that strong evidence currently exists for using systematic instruction to teach academic content and functional life skills as well as social and communication skills, but that limitations continue to exist regarding representation among students who have the most severe disabilities requiring intensive supports.

The sharing of this research can often be limited because the variety of descriptors used by the researchers (e.g., CHARGE syndrome) to describe the combined vision and hearing loss of the participants, and that dual sensory losses are often listed among other disability labels (e.g., sensory disabilities, severe disabilities), which make it challenging to identify deafblindness as a unique category (Parker, Davidson, & Banda, 2007). This research is critical in identifying effective intervention strategies for deafblind children.
that can be utilized to spread a greater understanding of deafblindness, increase identification of children and lead to more appropriate services to meet the needs of every child.

**Research Questions**

The following research question guided the design of the study and the analysis of the data: *From the perspective of case coordinators (e.g., special education coordinators, school psychologists) what factors (e.g., medical, educational, social) influence the identification process for children who are deafblind?*

**Significance of the Study**

Sensory loss related to deafblindness has an enormous impact on how a child relates to the world around them, including those within it. A child who has deafblindness does not have the same access to an environment as does their peers with typical vision and hearing. This makes identifying a child’s level of vision and hearing as early as possible imperative for providing appropriate interventions in a way that can support both senses simultaneously which is necessary to build connections within the environment. Thus, it is important to improve the identification process and ensure that the evaluative process considers the whole child in an attempt to identify the disability.

Identification and evaluation of students go hand in hand when making a disability classification for a child. Having accurate evaluation results influences the decisions made by educational teams to establish and deliver service. Research in the field of deafblindness has shown the absence of standardized tests that are normed or even suitable for use with children with the combined sensory losses, meaning that educational professionals are forced to use alternate instruments and methodologies to
assess abilities and skill development. Evaluation and assessment is possible, but the results generally are not comparable to those obtained for typical peers through standardized measures (Holt et al., 2006). For this reason, attention must be paid to the reliability and validity of an instrument and special focus given to the child’s current functional level vs. the predictive value of the assessment. Modifications and accommodations play a key role in making sure that test information is appropriate in regards to a child who does not have full access to their use of vision and/or hearing in the testing environment. Ignoring these factors while evaluating a child ensures a more negative result when gauging performance within the domain/s of development.

The evaluation of children with sensory loss may be a contributing factor for the underidentification of children due to the lack of appropriate assessment instruments related to deafblindness and the lack of understanding of issues related to deafblindness on the part of professionals who serve children. For example, the developmental scales, commonly used by psychologists, diagnosticians, and early childhood interventionists, present some serious problems when used with children who are visually impaired because many are based on the earliest developmental milestones and visual skills that require vision, and visual experience, and others that depend on visual monitoring (Holbrook & Koenig, 2000). Chen (2004) discussed the role of professionals working with children with hearing loss (e.g., speech language pathologists, teachers, audiologists) using secondary sources in assessing children who are deafblind and identified high risk factors that should be considered related to the development of listening skills, communication and language development.
With the improvement of the evaluation process for children with deafblindness, it is suspected that such children could be provided with more appropriate supports to meet their educational needs. Meaningful interventions begin the skill building needed for a child to participate successfully on a social level and lead to increased academic performance in the long-term. The potential goal for the proposed research is to contribute evidence to the field of education that offers an initial theoretical perspective associated with social factors that inhibit the identification of children with vision and hearing loss which inadvertently impact the development of interventions in these areas as part of the individualized instructional process.
Introduction

A review of research on identification practice was completed to examine how children with disabilities are depicted through the Federal Child Count. Each section depicts a representative sample across a range of disability categories followed by a discussion of suggested further research. It should be noted that a common theme throughout this research, across all disabilities groups discussed, were issues related to the disability definitions themselves, which are suggested as a source of the problem leading to inaccurate identification. This chapter is divided into three sections: identification in disabilities other than deafblindness, identification in deafblindness, suggested research.

Identification in Disabilities Other Than Deafblindness

The discrepancy in child counts illustrates that children with deafblindness are being identified across the range of disability categories offered by the law although the reason for identification of deafblind children outside of the label of multiple disabilities has almost no research-base. To better understand this phenomenon, a review of research related to the issues associated with under- and over-identification is being offered beginning with a focus on the sensory areas and extending out to themes suggested in other disability areas.
Visual Impairment Including Blindness

A review of research for the disability category of *Visual Impairment* showed a focus on the underidentification of children that have vision loss and an additional disability. Erin and Koenig (1997) use secondary sources to discuss the challenges of diagnosing a learning disability for a child with visual impairment due to reasons such as early difficulties in learning being attributed to the vision loss and the fact that the vision impairment may often times be more understood than the learning disability. They go on to state that sparse data on the co-occurrence of children with visual impairment and learning disabilities can lead to varying beliefs about the prevalence of children dealing with both disabilities and their needs for intervention. Evaluation tools for determining if a child has a learning disability, and assessment tools for monitoring progress, may not be valid for a child with vision loss. The challenges of using standardized tests for students with visual impairment and the importance of direct observation; interviews and functional diagnostic activities are recommended for a more accurate assessment of skills and determination of impact of the combined disabilities.

Li (2009) uses secondary sources to address some of the issues surrounding the identification of children with visual impairment and autism spectrum disorders. Studies have shown that behaviors of children with visual impairment may be similar to some documented behaviors of children with autism spectrum disorder, making it challenging to determine if a child should be identified as having one disability versus the other or both to ensure accurate representation. The lack of evaluation and assessment tools for children with autism and visual impairment, and the approximately 60% of children with multiple disabilities who also have visual impairment, suggest that underrepresentation/
overrepresentation among disability categories will be an issue.

Deshpande et al. (2009) studied the prevalence rates of visual impairment among students with hearing loss attending fourteen schools for the deaf in a large city in India to determine the nature and prevalence of ophthalmologic abnormalities. Visual acuity testing, refraction, external ocular examinations and fundoscopy were performed on 901 participants and tracked using excel. No detailed discussion was offered surrounding the analysis of data, but reports of results showed that most of the children had never had an eye exam and a large percentage of the sample (216/901) were found to have ocular problems. Due to the reliance on vision for students with hearing loss, the authors state that mandatory vision screenings should be required for students identified with hearing loss to ensure more accurate prevalence rates and appropriate services for children.

The lack of research among children with visual impairment and additional disabilities (determined or suspected) became a common theme through this review. Researchers such as Evenhuis (2007) use secondary sources to offer improvements to the identification process of children, but state that limited to no research exist to support claims for further scientific evaluation. In this case, a system is suggested to better identify young children with vision loss who have intellectual disabilities with the acknowledgement that there is no previous research to suggest this will be effective in improving prevalence rates. The need for a cost-benefit analysis in a test region is suggested as a next step with the acknowledgement that there is a social responsibility for providing these services that should outweigh cost.

**Hearing Impairment Including Deafness**

Research regarding the representation of children in the disability categories of
Hearing Impairment/Deafness focused on issues related to the classification of hearing loss and additional disabilities and the use of newborn hearing screenings. Guardino (2008) completed a review of literature on children with hearing loss and additional disabilities and found the following: related to the area of identification:

**Autism**—when compared to children with autism and hearing loss, children with autism and hearing did not demonstrate any specific characteristics that would lead to earlier diagnosis. One study also found that when a sample of children with autism were given an audiological exam, they were ten times more likely to have hearing loss then those in the general public.

**Emotional/ Behavior Disorders**—studies in the area showed that children with hearing loss were determined to have emotional/behavior disorders if there was the presence of one of the following traits: low achievement, aggressiveness, anxiety, hostile isolation, academic disability, uncontrollable behavior, hyperactivity and inattentiveness, self-destructiveness or being nervous-overactive. In general, it was found that children with hearing loss and emotional/behavior disturbance come from environments where communication was limited or they were socially neglected.

**Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder**—research in this area tended to focus on the assessment and the need for an interdisciplinary team and a multitude of methods (e.g., parent observation, detailed history, analysis of impulsivity) to more accurately assess children. It was found that when comparing the Test of Variables of Attention (TOVA) to the Attention Deficit Scales for Adults (ADSA) that the ADSA was a more reliable diagnostic tool for those with hearing loss. One study found a relationship between having a hearing loss and the ability to maintain attention
during a particular activity.

*Intellectual Disability*-research has shown that children with a more severe level of intellectual disability are diagnosed at early ages than those with milder levels. It was stated that most of the research related to children with hearing loss and additional disabilities was completed in the 1980’s.

Roth (1991) used secondary sources to discuss the challenges of appropriately classifying students with hearing loss and learning disabilities. Previous studies have made attempts to quantify the number of children with the two disabilities but cite that the procedures used to classify these children are unclear leading to a disparity in numbers. This disparity lends itself to a limited understanding of the characteristics and abilities of the range of children and an inadequate means for identifying the population accurately.

Canale et al. (2006) state that childhood hearing impairment is one of the most common congenital disorders. They used a retrospective study to examine the effects of newborn hearing screening on the age of diagnosis. Health records were reviewed for a sample of forty-six congenitally deaf infants to determine which had participated in a newborn hearing-screening program. The group mean age for those that had been identified as having a severe to profound hearing loss was 20.5 months (screened and unscreened) with a group mean age of only 6.8 months for those participants who had participated in the screening program. Analysis using t-tests were used to compare mean age at diagnosis; screened infants with/without risk factors, and unscreened infants with/without risk factors. Results showed that the difference was significant for those infants that had had been screened with/without risk factors (p<0.05). It should be noted
that the researchers still stated concerns for those children with milder loss who can go undiagnosed until they reach school age. Potential underrepresentation of children who have a progressive hearing loss is also a concern.

**Intellectual Disability (Mental Retardation until 2010)**

The review of research in the area of representation in the category of *Intellectual Disability* identified variables that lead to underrepresentation for students, as well as, a heavy focus on overrepresentation and disproportionality among students in minority and ethnic groups.

Oswald (1995) examined the representation of children in the category of *Intellectual Disability* and the correlates of state child count data using state-based eligibility criteria from previous research (Frankenberger & Fronzaglio, 1991) as well as demographic and economic data from the National Center for Education Statistics. The researcher hypothesized that variation in identification rates is related to variations in the state classification criteria and that those rates are also related to demographic and economic factors. ANOVAs were used to analyze relationships between intellectual disability percent and (a) state definition criteria, (b) state demographic variables and (c) state economic variables. Correlation analysis was conducted to examine each of the variables. Demographic and economic variable that were found to be significant were used in a stepwise regression analysis to develop a model for predicting variation. An ANCOVA was also conducted to examine the mean intellectual disability percentage across regions. Results showed significant differences across regions for intellectual disability percentages with a mean comparison revealing that western states identify
significantly fewer students than other regions, and significant correlations among three economic variables related to expenditure and the intellectual disability percentage.

In regards to underrepresentation, Daily, Ardinger and Holmes (2000) used secondary sources to examine how clinicians evaluate and assess children for intellectual disability. The three most common errors made by clinicians who overlooked the possibility of intellectual disabilities in young children included; 1) concluding that a child does not “look” intellectually disabled, 2) assuming a child who is ambulatory is unlike to be intellectually disabled, and 3) if the disability is considered, concluding it is not possible to test young children. It was also stated that the severity of a condition and the perceptions of parents and professionals regarding the disability may influence how and when a child is identified. Discussion on the social perception of a disability was found in the research in a number of disability categories.

A summary of results from studies that focused on minority and ethnic overrepresentation showed the following factors as potential contributors to the identification process: single test instruments being used to diagnose, assessment techniques that are not sensitive to ethnic and cultural differences, lack of multidisciplinary procedures for determining eligibility, and lack of parental participation in the decision-making process.

Autism

The prevalence rate over the last twenty years would make one question why the category of autism would be included in this critical review, but studies through the decades showed how children are represented has changed over time due to a better understanding of the disability. Increased awareness of autism has led to a subsequent
shift from incorrect specific learning disabilities identification to autism identification (Scull & Winkler, 2011).

To better understand prevalence rates, MacFarlane and Kanaya (2009) examined the eligibility requirements across the 50 states and Washington DC in special education criteria for the disability category of Autism. The authors stated that little to no research on the extent to which educational eligibility criteria among states caused the researchers to propose a study that determined the nature and magnitude for the interstate variability. They hypothesized the following:

1. All states will have experienced an increase in children receiving special education services under the autism category since 1990;
2. There will be a wide variability in the eligibility criteria for autism from state to state; and
3. Different diagnostic criteria will have an impact on the prevalence rates of children receiving special education services under the autism category.

The initial phase of the study included an examination of prevalence rates for the number of children categorized with *Autism* and the total number of children in special education over a seventeen-year period. Data was then categorized by geographic region. The second phase included the collection of special education eligibility criteria for the category of *Autism* from the 50 states and Washington DC. The state’s department of education website was searched with contact also being made to the head of the special education department via e-mail to locate the eligibility criteria. Due to only a 40% response, researchers went on to collect and analyze the legal code of every state and Washington DC. Two coders were used to categorize the diagnostic criteria within the
code by 4 themes that allowed for the measuring of differences and similarities across states. Analysis showed that variability among state eligibility criteria for children with autism could have an impact on prevalence rates. This study offers one of the only national perspectives related to disability data across states that could be located.

An additional issue faced for young children with autism, along with many of the other disability categories discussed, is the likelihood that a child will be classified as being developmentally delayed as part of a non-categorical early intervention system instead of being classified as having autism. According to federal law, this determination (Developmentally Delayed) can be used through the age of nine at which point another disability category must be selected. This is cited as another potential source for either under- or overrepresentation within categories.

**Emotional Disturbance**

The category of Emotional Disturbance is considered a high incidence disability based on the rates with which children are reported, but research in the area challenges the accuracy of these numbers based on the vagueness of the definition, state variation in eligibility criteria for classification, the influence of demographic and economic variables, and inconsistencies among the prevalence rates reported. Results of a review showed a common belief that the variation in state interpretations of the federally mandated eligibility criteria was a potential cause in the misrepresentation of children but studies on the underidentification had yet to verify consistent or systematic patterns that explained the phenomenon (Forness & Kavale, 1988). Using secondary sources, the authors found that, in the area of assessment, research has suggested that the use of functional assessments versus the standard norm-referenced approaches may provide a
more accurate account of the abilities of a child, although the lack of educational resources that meet the needs of such a wide range of students continues to be a problem.

Landrum (2000) used secondary sources to look at underidentification and additional issues related to identification for children with emotional disturbance. He found that while the federal government for years suggested that 2% of the school-aged population might have an emotional or behavioral disorder, and that previous research suggested that the rate of identification typically ranged from 0.5% to 1.0% (e.g., Rubin & Balow, 1975), that the true prevalence is more like 3-6%. Direct causes for these inconsistencies have been linked to the reluctance of educators to stigmatize a child with the label of serious emotional disturbance, shortages of qualified staff to serve those who have been identified, lack of economic resources to provide appropriate services to meet the child’s needs, and a tolerance for misbehavior in the regular education environment that may be considered by educators to be acceptable to avoid serving a child through special education resources.

**Identification in Deafblindness**

In this section the process of identification of children with deafblindness is reviewed using the following categories: guidance from the law, collecting the data, evaluating the child, and considerations for improving the child count process.

Efforts toward a comprehensive count have traditionally been driven by multiple factors including the federal law and initiatives related to a more accurate child count. To address the need for a more accurate count of children, the U.S. Department of Education’s Office of Special Education (OSEP) has supported an initiative to have a separate child count, or National Child Count of Children and Youth who are Deafblind.
(NCC), of children over the last three decades to provide accurate data on the population and to build capacity in regards to knowledge and awareness related to the disability (NCDB, 2014). Table 2.1 illustrates the NCC totals from across the United States for the most recent five years of the collection process:

<table>
<thead>
<tr>
<th>Year</th>
<th>National Child Count – Nationwide Totals</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>9,525</td>
</tr>
<tr>
<td>2011</td>
<td>9,387</td>
</tr>
<tr>
<td>2010</td>
<td>9,320</td>
</tr>
<tr>
<td>2009</td>
<td>9,200</td>
</tr>
<tr>
<td>2008</td>
<td>9,827</td>
</tr>
</tbody>
</table>

*Data are from the National Center on Deaf-Blindness (2014)

Table 2.1. *National Child Count of Children and Youth who are Deafblind - Snap Shot Number*

**Guidance from the Law**

Following the civil rights movement of the 1960’s, the free and appropriate public education (FAPE) of children of children with disabilities, has been of national focus since the passing of the Education for All Handicapped Children Act of 1975. The philosophy behind this law influences the use of the medical model to label children in disability categories for the purposes of providing appropriate education. The implementation of the model has assisted educators in identifying disability groups, although problems related to accuracy still exist with the issue of some disability groups being overrepresented or underrepresented, raising questions related to the
appropriateness of the educational interventions being provided. This provision of FAPE begins with the identification and assessment of a child’s abilities that allow educational teams to target interventions to meet the needs of students.

It is through such large-scale legislative efforts that we have seen a change in the way children with disabilities have been acknowledged and educated over time. But Triano (2000) challenges the effectiveness of the overall educational system for children with disabilities, which is based on what was originally European legislation from the late 19th century. She questions whether we have really seen a shift in the way children with disabilities have been educated over time in terms of access to educational resources and peer groups. Although many educators would view the shift toward identification and inclusion as a success, disability theorists have argued that, as fifteen percent of the nation’s population, people with disabilities make up the largest physical minority group within the United States, and have had their civil rights violated over time with far less attention than any other minority group (Baglieri et al., 2010).

The philosophy behind the Education for All Handicapped Children Act, now known as the Individuals with Disabilities Education Act (IDEA), has been to ensure services to children with disabilities throughout the nation and lead to a more equitable education compared to those students without disabilities. By governing how states provide early intervention, special education and related services to more than 6.5 million eligible children with disabilities (Building Legacy, nd), the law holds States accountable for children where there is a suspicion of loss as well as those who have been identified with a disability as part of child find efforts.
Using a medical model, children are evaluated by diagnosticians and placed into one of thirteen disability categories related to Part B services. A further breakdown of these categories highlights those that happen at a lower incidence, or 1% or less, which include each of the sensory disabilities. Early intervention, or Part C services, uses broader categories including development delays or at-risk groups to identify children.

Of the sensory disabilities, children with deafblindness represent one of the lowest incidence, yet most diverse groups of learners that make up an extremely heterogeneous group, whose sensory losses are frequently accompanied by additional physical and cognitive disabilities. (Muller, 2006). Such children may be categorized as being deafblind with either a congenital or progressive loss of the senses that can make a child’s level of functioning perplexing to parents and service providers. National awareness of the unique needs of the population of children who were born with a combination vision and hearing loss through the rubella outbreak in the 1960’s shifted focus to the need for a separate funding category for the population that was established in 1969 (Baldwin, 1992).

For this category the law offers educators guidance through a federal definition but it is important to note that although the federal definition is available, it has been criticized for its breadth, and States have some discretion related to using a modified definition for children reported through the Federal Child Count. Professionals in the field acknowledge this issue and are currently discussing their concern with legislators nationwide to improve the practice of identification. The question lingers as to whether this is a contributing factor to the discrepancy between counts and the possible underrepresentation of children (Ward & Zambone, 1992).
Understanding what guides decision-making for educators and families is key to addressing the issues associated with child identification leading to over- and under-representation across disability categories. Feminist theorists challenge the potential social injustice for persons with disabilities and question why such inequality has existed for so long for such a large minority (Wendell, 1989). Within this framework, Wendell also asserts that disability is a socially constructed, not biological, reality. This theoretical belief challenges the current medical model that is in place to identify children through categorization based on a disability label. Triano (2000) states that the medical model stigmatizes and dehumanizes children with labels, which she states often lead to lowered teacher, peer, and personal expectations based on individual perceptions related to the disability. For this reason, she supports the use of a non-categorical system that would be contradictory to the current state and federal law that supports special education.

It is through the investigation of this law that potential factors that might contribute to the underrepresentation of children can be delineated. As part of the requirements related to Part C services, infants and young children are initially identified using a limited number of broad categories such as developmentally delayed. It is not until they reach the age of three, and become eligible under Part B of IDEA, or school aged services, that a more specific disability category is required. Even still, the federal definition addresses a general range of disability without offering specific levels of vision and/or hearing loss. This change in categorical systems, and broad categorization, could lead to delayed identification through the FCC and later referral for inclusion on the National Child Count for Children who are Deaf-Blind.

Additionally, the low incidence of children who are deafblind may lead to a lack
of mainstream exposure and misconceptions related to the range of functioning in the areas of vision and hearing for most children. The socially constructed conceptions of deafblindness have no doubt been impacted by the legacy of Helen Keller, who had profound losses in each area. Contradictory to this specific perception of deafblindness, Fredericks and Baldwin (1987) state that approximately ninety four percent of children identified through the National Child Count of Children and Youth who are Deafblind have some usable vision or hearing, which is a statistic that has stayed consistent over time.

**Collecting the Data**

Historically, the deafblind child data has been collected from two sources, including the Office of Special Education Programs (OSEP) FCC and the NCC, for children ages birth through twenty-one since 1986 (NCDB, nd). The idea of two counts can be perplexing because it is not representative of how children are counted within other disability groups who are typically identified primarily through the FCC alone.

Muller (2006) addresses this discrepancy by stating that since the majority of children with deafblindness do have additional disabilities, they are not included in the FCC as deafblind. Through research including open-ended interviews with ten deafblind projects funded through OSEP, Muller was able to identify two major reasons participants felt there was a discrepancy including; children who are deafblind being identified as “multi-handicapped/disabled” by the educational team and the misconception that services are delivered based on disability, meaning children labeled as “multi-handicapped/disabled” would receive more. These assumptions do not support the intent of the law and its focus on evaluation based individualized services to meet the
unique learning needs of every child and the idea of self-concept on a broader scale for individuals with deafblindness as a unique social group with relevance within the general population (Stets & Burke, 2000).

Although these discrepancies exist nationwide between the counts, two examples of the differences in Ohio and California are illustrated in Table 2.2 and Table 2.3 to support the point. As with most of the research and commentary on child identification data on deafblindness, Baldwin (1992) uses secondary data sources to address the discrepancies and asks the question: Does the label of “deaf-blind” carry with it the need for extraordinary intervention strategies? If the combination of a hearing and a vision loss can best be dealt with by utilizing unique teaching strategies that are different from those that are effective with the single disabling conditions (e.g., loss in vision or hearing alone), then it becomes imperative to know who has a dual sensory impairment.

<table>
<thead>
<tr>
<th>Year</th>
<th>NCDB National Count on DB-OH⁸</th>
<th>OSEP Federal Child Count OH⁹</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>366</td>
<td>42</td>
</tr>
<tr>
<td>2011</td>
<td>349</td>
<td>50</td>
</tr>
<tr>
<td>2010</td>
<td>356</td>
<td>47</td>
</tr>
<tr>
<td>2009</td>
<td>329</td>
<td>47</td>
</tr>
<tr>
<td>2008</td>
<td>375</td>
<td>57</td>
</tr>
</tbody>
</table>

a Data are from the National Center on Deaf-Blindness (2013)
b Data are from the Ohio Department of Education (2013)

Table 2.2. National Child Count Data compared to Federal Child Count for Ohio over the last five reporting cycles for children ages 3-21
<table>
<thead>
<tr>
<th>Year</th>
<th>NCDB National Count on DB-CA&lt;sup&gt;a&lt;/sup&gt;</th>
<th>OSEP Federal Child Count CA&lt;sup&gt;b&lt;/sup&gt;</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012</td>
<td>926</td>
<td>128</td>
</tr>
<tr>
<td>2011</td>
<td>925</td>
<td>126</td>
</tr>
<tr>
<td>2010</td>
<td>915</td>
<td>133</td>
</tr>
<tr>
<td>2009</td>
<td>840</td>
<td>142</td>
</tr>
<tr>
<td>2008</td>
<td>857</td>
<td>170</td>
</tr>
</tbody>
</table>

<sup>a</sup> Data are from the National Center on Deaf-Blindness (2013)

<sup>b</sup> Data are from the California Department of Education (2013)

Table 2.3. *National Child Count Data compared to Federal Child Count for California over the last five reporting cycles for children ages 3-2*

**Evaluating the Child**

The evaluation of children with sensory loss may be a contributing factor for the underidentification of children due to the lack of appropriate assessment instruments related to deafblindness and the lack of understanding of issues related to deafblindness on the part of professionals who serve children.

Holbrook and Koenig (2000) state few teachers of students with visual impairments are prepared or experienced in assessing young children and that there are few standardized instruments designed for children with visual impairments while completing the process to identify a child. The influence of additional disabilities in the process of evaluation has also been addressed by Fellinger et al. (2009), who studied the use of auditory and visual assessments with 224 individuals of an Austrian residential facility who were identified as having intellectual disabilities. Prior to the study, 12.5% had been identified as having a hearing impairment, whereas 17% of participants had previously been identified as having a visual impairment. As a result of comprehensive
assessment in both the areas of visual and hearing impairment, results showed that the 
severity of dual sensory impairment seemed to determine the probability of the 
identification. Only those with the most profound degree of deafblindness had a good 
(80%) chance of being identified by their caregivers. This led to an increase of 46% being 
identified as having a hearing impairment and 38.4% with a visual impairment.

Additional empirical research in the use of vision and hearing evaluations for 
individuals primarily identified with a disability that is not deafblindness could 
potentially lead to an increase in the identification of vision and hearing deficits in others 
and address specific interventions for increasing the levels of functioning to enhance the 
lives of the individuals. Educators and researchers have also suggested the increased use 
of functional assessments in supporting the unique needs of students.

Dunlap (1985) conducted a quantitative study with 251 individuals who are 
deafblind to determine the effectiveness and practicality of a functional classification 
system related to education. The participants were grouped by functional level within 
eleven activity variables and a cluster analysis was performed. Results showed the groups 
could be most clearly differentiated from one another in the areas of gross motor, 
language, leisure activities and socialization. This challenges the notion that grouping 
based solely on disability will provide enough automatic differentiation unique to the 
individual’s needs.

Using a qualitative approach, Ward and Zambone (1992) identified key points 
related to the importance of the identification of children who are deafblind through an 
accurate child count by surveying deaf-blind project coordinators across the nation. They 
state that the count affects not only local, state, and federal policies and school programs,
but additionally; 1) the number of and nature of teacher training programs, 2) the development of transitional and support services for post-school placement, 3) the responsiveness of community health and social service agencies to these students and their families, and 4) research in such diverse areas as the impact of disabilities, best practices and medical needs.

Results showed two areas that could be addressed to improve the discrepancy between counts: use of a standardized definition across States, and efforts by OSEP to improve the accuracy of the etiological information that is reported. Although this study was limited to the perspectives of only deafblind project staff, which is not uncommon within the research in the field, the results provide practical information that can continue to be evaluated with other deafblind project staff, as well as other populations, including parents and school evaluation team members, to make efforts toward a more accurate count of children.

In regards to the unique characteristics that separate deafblindness from other disabilities, Hoevenaars-van den Boom et al. (2009) studied the behaviors of ten individuals with deafblindness (five who had also been identified with autism) to differentiate characteristics between the two groups. Adapted instrumentation, the Observation of Characteristics of Autism in Persons with Deafblindness, was created using items from existing diagnostic tools in autism. Based on observation from an evaluation panel of experts in both areas, some behaviors, including openness for contact and communicative signals, were identified that can determine the difference between diagnoses. This further supports the notion that children with deafblindness have a unique
set of characteristics that could be influential in the identification process but research is lacking in the area.

In a breakthrough study, Rowland, Stillman and Mar (2010) used a survey approach with educational professionals across the nation to begin to determine the types of assessment tools that were being used with children who are deafblind that address cognition, communication and learning styles. A striking result was that there were no universally accepted instruments for assessing young children. Suggested reasons for this disconnect showed a lack of awareness and access to tools that are appropriate for deafblind children among professionals. It would be beneficial to determine if these practices hinder the evaluation process for children during the initial identification process and educational services planning phases that are mandated by federal law.

Considerations for Improving the Child Count Process

It has been suggested that perceptions about deafblindness are an influential factor in the identification of children, although this is supported by limited research, including anything with a participant pool that includes related service personnel and other educational professionals (e.g., special education directors, school psychologists) that are not associated with a deafblind project. As discussed previously, Muller (2006) conducted a qualitative study using an interview protocol with deafblind project coordinators to identify concerns related to the discrepancy in the NCC and FCC data. Using a convenience sample from ten deafblind projects, the following are policy recommendations related to early identification that were offered:

- Provide appropriate follow-up services to young children who fail the newborn hearing screening and/or are identified with a syndrome that closely relates to
deafblindness.

- 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.

The second point provides a reoccurring theme in the research that suggests that the definition of deafblindness itself is a barrier to identification. Beyond the study mentioned, no formal research could be found that examines the use of alternative terminology, which may in fact be the first step in influencing perceptual change of those who make child count disability determinations.

**Suggested Research**

The review of literature on the identification of children with disabilities provided suggested research to improve the representation of children reported through the child count that included focus on population-based studies, eligibility criteria across states and educational teams that classify children. Lewitt (1996) states that if the primary purpose of the Office of Special Education Programs’ data collection system is to count the number of children in special education programs being served with federal funds, the system, unless fundamentally altered, will continue to be unable to provide national information for policymakers and educators on the appropriateness of individualized services delivered. He suggests the implementation of studies that look at the collection of population-based data on the prevalence of disabilities among children. This approach
would go beyond the analysis of what have been termed as “broad” or “vague” disability definitions and investigate the specific conditions and levels of function within each category to better understand the students represented.

Schull and Winkler (2011) examined the stark variation among state figures that call into question the extent to which true incidences of a disability vary among state populations, or to which some states over-identify or under-identify students with disabilities. Findings showed that in some states children could be reported in one category *within another* making an even greater lack of consistency. They suggest further research into the eligibility requirements across states, including a focus on the definitions used which are left up to the discretion of states, to better understand these inconsistencies and improve the potential for trend analysis.

Study of the process that special education evaluation teams use to make decisions regarding classification in local school districts is needed to examine what additional variables play a role. As stated by Oswald (1995), if the process of identification of students is to possess reasonable social validity, and if the analysis of special education data is to contribute meaningfully to educational planning and policy, a clearer understanding of the process is needed involving the explication of the objective and subjective forces which influence the decision. These forces impact how children are classified, and in states like Ohio which use a funding formula to determine a per-pupil cost for students depending on which of the six levels the disability falls, influences the amount made available to support individualized services based on the evaluation of the educational team.

In regards to disability research in general, Guardino (2008) suggests conducting
valid and reliable research using (a) intervention designs (e.g., multiple baseline, control group, and single subject), (b) comparison of existing databases, (c) instruments normed on disabled populations, and (d) longitudinal designs to come closer to standardizing criteria for specific disabilities.

Identified factors that may contribute to the underidentification and underreferral of children through child counts could include the socially constructed perception of what it means to have a specific disability and the lack of awareness of stakeholder groups in their role in identifying children accurately. Meaningful information could be gathered through qualitative research that begins to identify factors and generate theory related to the process. The potential implications for the current process have shown to be: inaccurate representation of the population, decreased focus on educational training for parents and service providers based on a larger representation of children, decreased federal and state funds for educational services, and decreased reliability and validity in research based on data offered as part of the count.

This dissertation study began an initial investigation to identify specific factors within educational evaluation teams, specifically case coordinators, which address the discrepancies in child counts for young children who are deafblind, including the further exploration of the socially constructed concept of deafblindness. It is believed that the results will contribute to the field of education by offering a broader understanding of the perceptions and perspectives that shape the concept of disability and the process for identification.
Chapter 3: Methodology

Introduction

The purpose of this dissertation study was to begin an exploratory study using qualitative methods that examined the factors that contribute to the underidentification of children with deafblindness through child count data in a large, midwestern state. Existing research on the topic of identification for children with deafblindness has primarily focused on the perspectives of service providers in the field who work with state deafblind projects. As these individuals offer many insights into the reasons they believe children are under-identified as having deafblindness, or misidentified under another disability category (e.g., visually impaired, multiple disabilities), a broader perspective from additional educational professionals is needed to more accurately understand the issues associated with the process. For this reason, the experiences and perspectives of case coordinators that coordinate and evaluate children for special education services in local school districts and determine disability classifications were examined.

According to Crooks (2001), to uncover and better understand basic social processes, grounded theory is ideal for exploring integral social relationships and the behavior of groups where there has been little exploration of the contextual factors that affect individual’s lives. Grounded theory provides an investigative structure for the
natural emergence of information and evolving analysis that guides the researcher to the
development of a theory that enhances understanding of a social phenomenon. Key
features of grounded theory include (Charmaz, 2006):

- Simultaneous collection and analysis of data
- Creation of analytic codes and categories developed from data and not by pre-
  existing conceptualizations
- Discovery of basic social processes in the data
- Inductive construction of abstract categories
- Theoretical sampling to refine categories
- Writing analytical memos as the stage between coding and writing
- The integration of categories into a theoretical framework

To gain greater insight into the perceptions of case coordinators within multiple
districts an onsite interview approach was used to begin to gather data regarding the
process for identifying and classifying children as part of the special education process.
Data obtained from participant interviews was coded to establish themes using the
constant comparative method. Constant comparative method guided the initial
development of theory regarding the identification process for children. This chapter
outlines the study using four sections: a description of participants, methods, analysis and
trustworthiness.

Participants

In preparation for the application of the qualitative approach, state child count
data was collected and reviewed to determine twenty target districts for participation.
Participant selection began with the collection of state child count data for children who
were reported as having deafblindness for the academic year of 2012-2013. This
information is collected annually from districts and reported to OSEP as part of the FCC from state educational agencies.

The review identified forty-eight districts that had reported the existence of a child categorized under the label of deafblindness during that time period. The department of education’s typology of school districts was then utilized to categorize districts into four groups. This typology was developed as a means to stratify districts for research purposes using several data sources so that classifications could be made based on demographic and geographic characteristics (ODE, 2013). The major groupings as described in Table 3.1 Description of Major District Typology Groupings are referred to as follows: rural, small town, suburban and urban.

<table>
<thead>
<tr>
<th>Rural</th>
<th>Small Town</th>
<th>Suburban</th>
<th>Urban</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>General Factors</strong></td>
<td><strong>General Factors</strong></td>
<td><strong>General Factors</strong></td>
<td><strong>General Factors</strong></td>
</tr>
<tr>
<td>• Average student poverty</td>
<td>• Average student poverty</td>
<td>• Low student poverty</td>
<td>• High student poverty</td>
</tr>
<tr>
<td>• Small population and enrollment</td>
<td>• Average population and enrollment</td>
<td>• Large population and enrollment</td>
<td>• Very large population and enrollment</td>
</tr>
<tr>
<td>• Small student minority population</td>
<td>• Average student minority population</td>
<td>• Average student minority population</td>
<td>• High student minority population</td>
</tr>
<tr>
<td>• Significant agricultural tax base</td>
<td>• Mix of agricultural and professional employment</td>
<td>• Primarily professional employment</td>
<td>• Average parental educational attainment</td>
</tr>
<tr>
<td>• Low parental educational attainment</td>
<td>• Average parental educational attainment</td>
<td>• High parental educational attainment</td>
<td>• Mix of professional and nonagricultural employment</td>
</tr>
<tr>
<td><strong>Unique Factors</strong></td>
<td><strong>Unique Factors</strong></td>
<td><strong>Unique Factors</strong></td>
<td><strong>Unique Factors</strong></td>
</tr>
<tr>
<td>• Small tax base</td>
<td>• Low population density</td>
<td>• Large tax base</td>
<td>• High population density</td>
</tr>
<tr>
<td>• Low population density</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Ohio Department of Education (2013)*

Table 3.1. Description of Major District Typology Groupings
As mentioned, these major groupings were then categorized allowing for a total number to be determined across groups (Table 3.2). It should be noted that four districts did not fall under the major groupings categories due to the nature of their programming (e.g., joint vocational, charter). For the purposes of this study, and the restriction of time available, it was determined that these educational options for families would benefit from more in-depth examination as part of future research on the topic.

<table>
<thead>
<tr>
<th></th>
<th>2012-2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>6</td>
</tr>
<tr>
<td>Small Town</td>
<td>12</td>
</tr>
<tr>
<td>Suburban</td>
<td>15</td>
</tr>
<tr>
<td>Urban</td>
<td>11</td>
</tr>
</tbody>
</table>

*Department of Education Data

Table 3.2. District Typology Totals for Children Reported as Having Deafblindness in 2012-13

Each of the major groupings were then entered into the Research Randomizer (Urbaniak & Plous, 2013), an electronic sample randomizing tool developed by Geoffrey C. Urbaniack in 1997 using complex algorithms that are supported through the Social Psychology Network, to determine a random sample for the order of participation for the twenty districts under study. Although this number may seem ambitious for a dissertation study, a staggered approach (Table 3.3) was utilized to help determine the actual point of saturation, or redundancy, when it was no longer necessary to collect additional data (Morrow, 2005). Although it was anticipated that the point of saturation would be at 6-7 interviews, it was truly determined following the thorough review of multiple data
sources with agreement from the researcher and research consultant who were an active part of the process for analysis, as discussed further as part of the Analysis section.

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Table 3.3. Study Timeline for 2014-15 Illustrating Staggered Approach for Districts
The staggered approach for setting up interviews with districts within major groups began with contact being made to the first district that was selected in each of the four categories (e.g., rural, small town, suburban, rural). Administrators that focused on the provision of educational services (e.g., directors of pupil services or special education directors) were contacted to assist in identifying case coordinators for interviews. The administrators were provided with information about the background and purpose of the study, and then asked to suggest the name of an individual that would be utilized if an evaluation referral were received for a child with a suspected combination of vision and hearing loss. These professionals, case coordinators, were the focus of this qualitative study because research suggests that they are trained in evaluative techniques, coordination of service and are consistent members of educational teams for all students (NASP, 2014).

Methods

The exploratory function of this study attempted to establish a theoretical framework using methods that support grounded theory. The environments and interactions of those under study were examined through the establishment of codes and categories to generate theory around the social phenomenon of classifying a disability. The theory that emerged shows a set of relationships that offer a plausible explanation of the phenomenon under study (Straus & Corbin, 1998). The version that most aligns with the ideas of Anselm Strauss influences how elements from the data were grouped and contextualized to formulate theory related to the ideas and perceptions around deafblindness and the impact on disability determination. The application of a grounded theory approach used a conceptual model that provides a set of systematic procedures for
collecting and coding data that facilitated the development of categories related to the research question.

Exploratory research intends to ask broad questions that begin the process of contextualizing an issue. The field of deafblindness has limited research in the area of identification and those small-scale studies that have been completed show a tendency for using similar participant pools (e.g., deafblind project staff) to speculate as to why school personnel report children with vision and hearing losses as having disabilities other than deafblindness. The following research question was addressed in this study:

*From the perspective of case coordinators (e.g., special education coordinators, school psychologists) what factors (e.g., medical, educational, social) influence the identification process for children who are deafblind?*

Straus (1987) supported the use of both “self” (specific understanding from past experiences) and existing literature to provide sensitivity that may be used to stimulate theoretical conceptions and generate hypotheses. It is for this reason that case coordinators as members of the evaluation team have been selected as participants. These individuals use a combination of policy-based and practically-based knowledge to dictate the practice of evaluation for children with disabilities across their professional domains resulting in the reporting of classification data.

According to Canter (2006), school psychologists are often assigned to leadership roles on school teams, and even when they are not, they are regarded as leaders in regards to evaluation, assessment and intervention. These leadership roles may be especially important in small town or rural districts where special education administrators and services may be combined with other responsibilities, or contracted out to educational
service centers, making the school psychologist the point person for case coordination. Although it could be argued that changes in legislation related to education and intervention have shifted the focus away from a primarily evaluative purpose for school psychologists, it is still extremely common for a majority of their time to be devoted to the area of special education to determine eligibility due to current district funding models. For this reason, school psychologists were included in the participant pool to acquire a more accurate perspective from the various school districts that were represented. The designation of a school psychologist for participation was made through the primary contact (e.g., special education administrator) as they felt it was most appropriate in representing their district.

To begin the investigative process for identification, administrators were approached to determine who would participate in the interview process. They were contacted using a letter (Appendix A) that outlined the purpose of the study and details surrounding informed consent (Appendix B). They were then asked to identify a case coordinator through a follow-up phone call (Appendix C) who would be part of the evaluation team for a child referred for special education services with a reported combination of vision and hearing loss. The case coordinator was then contacted by phone (Appendix D) with follow-up by email (Appendix E) outlining the purpose of the study and details surrounding informed consent. They were then asked to participate in an onsite interview. In all cases, a letter of support for the proposed research was requested from the district leadership team.

To maintain alignment with methods that support grounded theory, a semi-structured interview approach was used to generate data. Semi-structured interviewing is
more flexible than standardized methods such as the structured interview or survey. Although the interviewer in this technique has some established general topics for investigation, this method allows for the exploration of emergent themes and ideas rather than relying only on concepts and questions defined prior to the interview.

A standard set of questions guided the interview process for the interviewer and participant (Appendix F). These questions were determined using feedback from an expert review panel in the field of deafblindness to establish reliability and validity. The expert review panel included:

- Three practitioners in the field of education who have had a minimum of five years experience supporting the educational needs of students with sensory impairments
- Two licensed school psychologist who have experience as part of educational teams for students with sensory impairments

As part of the interview process, each question was asked in a similar order to allow for more consistent comparison between answers being given while allowing opportunity for further probing for information that seemed relevant to the discussion. These probes offered opportunity for further exploration on emerging topics/areas during the interview.

The interviewer’s role was to engage and encourage the participant by building a rapport and maintaining awareness of word choice and body language throughout the interview. A limited amount of reciprocal engagement was offered with most interviewee responses being followed only by probing questions that helped the researcher gain a greater understanding around the phenomenon that led to the development of emerging
theory. Exploration and clarifications of any comments made supported the ongoing analysis of data. Individual interviews took place in a neutral setting, or a setting of choice, at a convenient time for each participant. As outlined in the letter, all interviews were recorded using a portable audio device to minimize the interviewers reliance on note-taking during the session.

As data was collected it was then transcribed using a password protected personal computer to allow for the comparison of memos collected during the interview process so that all information was used for iterative analysis. All identifiable information was removed and each participant was assigned a code to be utilized throughout the research process. This code was stored on a separate external drive and will be destroyed following the guidelines offered by the University’s Office of Responsible Research Practices. Additional safeguards focused on data encryption with scheduled bi-weekly backups of information on the personal computer and all external drives.

**Analysis**

Data analysis for this qualitative study employed the use of the constant comparative method to generate the initial theoretical perspective that will offer clearer direction for future study to the field of education. This methodology was investigative in nature using verification and deduction to better understand the social process, and through data collection with concurrent analysis, allowed for the emergence of theory to inform and enhance subsequent data collection.

A constant comparative framework was used as the primary method for data analysis. Constant comparative method provided a mechanism for the development and refinement of code to establish thematic categories. The comparison of various data sets
from interviews is extensively reviewed throughout the process of collection looking for alignment and exceptions that can build understanding of the concepts being discussed. A team of research consultants from the field of deafblindness was proposed to determine verification of established codes. Criteria for membership on this team included:

- Minimum of five years experience supporting the educational needs of children with deafblindness
- Familiarity with methodologies in qualitative research
- Experience working with educational team members (e.g., teachers, parents, related service providers), that may include school psychologists, to establish service provision

Samples from every interview transcript, along with notes highlighting suggested themes, were electronically shared using non-identifiable information within encrypted files for the purpose of review. This use of triangulation across multiple data sources offered confirmatory analysis leading to the validation of information and an increase in the level of trust associated with the study. The ever-changing understanding of the co-review provided also guided analysis and inquiry for further in-depth understanding of the phenomenon.

Constant comparative method breaks data into discreet incidences that are coded and constructed into conceptualized categories. These conceptual categories can be both descriptive and explanatory and are used to develop theoretical insights into the social process being studied (Guba, 1981). The constant comparison of data lends itself to the adaptation of categories and their relationships. As Taylor and Bogdan (1984) state, in the constant comparative method the researcher simultaneously codes and analyzes data
in order to develop concepts; by continually comparing specific incidents in the data, the researcher refines these concepts, identifies their properties, explores relationships to one another, and integrates them into a coherent explanatory model.

Participant interviews were presented using a semi-structured approach where the general topic was presented and a set of questions was asked in a similar order. As the information was exchanged, and relevant concepts emerge, probing questions were asked for clarification and verification purposes. This structure allowed for a more consistent comparison of data, using the set of questions across interviews, and the explored conceptual information gathered through additional probing, to generate category development through the use of coded information. Strategies to support a more encouraging tone for participant responses was the focus of the interviewer, with minimal personal or reciprocal sharing on the interviewers end, so that individuals were more comfortable sharing their in-depth views on topics.

Heath and Cowley (2004) maintain that rather than emphasizing deduction followed by verification, it is necessary to institute deductive practice followed by validation and elaboration for topic exploration and further data comparisons. It is believed that the suggested method is best suited for gathering a comprehensive and valid response to the research question. The constant comparison of data through the interviewing process means that the information was regularly coded for organizing and understanding of its purpose. According to Strauss and Corbin (1998), analysis should include open, axial, and selective coding as a mechanism for purposive categorizing of data as described:
• *Open coding* refers to the process of generating initial concepts from data that are then labeled and described to better understand the features under study; what is happening in the data? What is the basic socio-political problem? What accounts for it? What patterns are occurring? (O’Callaghan, 1996)

• *Axial coding* refers to the development and linking of concepts into conceptual families-coding paradigms showcasing relationships between categories.

• *Selective coding* refers to the refining and validating of these relationships with formal positioning into theoretical frameworks where a core category exists that relates to all categories. From this core category a central phenomenon is established around which all categories are based that leads to the generation of theory.

This coded information allows for the understanding of inter-relationships among concepts leading to the establishment of a core category as the main theme. The main theme then becomes the substance of what is happening in the data. Glaser (1978) summarizes the criteria a core category must meet:

- it must be central and account for a large proportion of behavior
- it must be based on recurring themes drawn from the data
- it must relate meaningfully to other categories
- analysis should be based on the core category
- it should be modifiable

According to Heath and Cowley (2004) the theory that is derived using the core category becomes a perspective or analytic stance that may subtly suggest linkages and help achieve plausibility and completeness while maintaining complexity and dynamic
flow. In alignment with the principles of grounded theory, it is a well-supported theory, and not the sole theory, which addresses the research questions being asked. Glaser and Strauss (1967) suggest that researchers should judge how good the theory is by using:

- Closeness of fit between theory and data
- How understandable it is (by a lay person working in the field)
- How it can be generalized to diverse situations
- Whether it can allow some control or change of the situations

As theoretical perspectives began to generate within the analytic process these questions were asked. Any limitations that were identified are addressed and discussed for the reader’s review.

**Trustworthiness**

Glaser (1978) suggests criteria for assessing the rigor or quality of a study include: fit and relevance (data and category fit from constant comparison), workability (integration of categories into the core category), modifiability (theory has all concepts incorporated in and can be altered when new data arises). Efforts to reflect the trustworthiness and rigor of this qualitative study were employed through the use of constructs developed by Egon Guba. As Williams and Morrow (2009) suggest, research paradigms can be best understood, not by discrete and separate points of view, but rather as on a continuum, beginning with postpositivism and moving on through interpretivism, constructivism, social constructivism, and ultimately critical/ideological and postmodern/poststructural theories.

The exploratory nature of this work aligns best with the most traditional form of qualitative research that maintains a level of distance between the researcher and participants. Analysis was shaped by outside verification leading to collective findings.
that offer response to the research question. Shenton (2003) states that these constructs correspond to the criteria employed by the positivist investigator and include: credibility, transferability, dependability and confirmability (Table 3.4).

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<th>Naturalistic Term</th>
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<td>Transferability</td>
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<td>Dependability</td>
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<tr>
<td>Neutrality</td>
<td>Objectivity</td>
<td>Confirmability</td>
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</table>

*Guba, E (1981)*

Table 3.4. *Scientific and Naturalistic Terms Appropriate to the Four Aspects of Trustworthiness*

Measures that were employed in this study to support these four parallel criteria include:

*Credibility*- to ensure that the study addressed the internal validity, or addressed what is intended in a consistent manor, measures included the purposive sampling that was guided by the school/district administrator across districts. Potential participants were also given detailed information about the research and given the option to refuse to participate at any time. Each session began with time dedicated to building a rapport in an attempt to allow information to flow more freely. To address creditability and maintain the integrity of the data, evidence provided through the sharing of direct quotes and suggested themes with the deafblind research consultant for the purposes of co-analysis.
Transferability- the challenge in suggesting generalizability using qualitative methods is that the study participants are often limited in number and specific to an environment. Guba and Lincoln (1994) suggest the researcher address generalizability by offering sufficient contextual information about the fieldwork and a thick description of the phenomenon under investigation. This technique allows the reader to determine transferable inferences versus the researcher who only knows the sending context. A rich amount of data was collected from each participant so that various viewpoints were interpreted. Cross-analysis through methodological triangulation was also employed with the research consultant from the field of deafblindness to better support the development of themes and categories.

Dependability- the reliability of the study was addressed through the use of overlapping methods through individual interviews. The sharing of detailed information regarding the clearly articulated methods of the study and their effectiveness also supported efforts toward consistency for future researchers.

Confirmability- to address reflexivity, objectivity and researcher bias, the development and sharing of an audit trail that described the course of research step-by-step provides the reader with the levels of consistency that were adhered to. The transparency of the study offers the reader insight into data and analysis that support findings that address the very specific phenomenon being research.

The methodology described was proposed and approved as Category 2 Exempted Research by The Ohio State University Office of Responsible Research Practices under protocol number 2014E0518.
Chapter 4: Findings

Introduction

The purpose of this dissertation was to begin an exploratory study using qualitative methods that examined the factors that contribute to the underidentification of children with deafblindness through child count data in a large, midwestern state. Existing research on the topic of identification for children with deafblindness has primarily focused on the perspectives of service providers in the field who work with state deafblind projects. As these individuals offer many insights into the reasons they believe children are under-identified as having deafblindness, or misidentified under another disability category (e.g., visually impaired, multiple disabilities), a broader perspective from additional educational professionals is needed to more accurately understand the issues associated with the process. For this reason, the experiences and perspectives of case coordinators that facilitate and/or evaluate children for special education services in local school districts and determine disability classifications were examined.

The investigative structure of the grounded theory approach guided analysis as data was coded and compared to establish themes to support the development of theory around the phenomenon of classification. State child count data for the academic year of 2012-2013 identified 48 districts that reported having children with deafblindness. It
should be noted that four districts did not fall under the major grouping categories due to the nature of their programming (e.g., joint vocational, charter). These districts represented four typologies including: rural, small town, suburban and urban. Following the categorization and randomization of districts a staggered approach was used to invite one district from each category to participate in a round of individual interviews. Of the twelve school districts that were invited to participate in the three rounds of onsite interviews for this study, a total of nine districts accepted and were represented to capture contextual factors that influence the identification of children with deafblindness. The fourteen participants included special education/services coordinators/directors, school psychologists and one teacher of the visually impaired with an average of 20 years of experience in the field of education (Table 4.1).

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<th># Years in Education</th>
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<td></td>
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<td>- Special Services Coord 9-12/ HS Asst Principal</td>
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<td></td>
<td>- Teacher of Visually Impaired</td>
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<td>9</td>
<td>Small Town</td>
<td>- Director of Student Services</td>
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Table 4.1. District Participant Demographics
Through the constant comparison of data being collected it was believed by the end of round three that a point of saturation had been reached with no new data being presented. The participant responses led to the initial, focused and axial coding of data examining themes and sub-themes which developed into the following five factors that influence the identification of children with deafblindness based on participant response: previous records, data, federal/state requirements, evaluation team members, referral sources as illustrated in Figure 4.1.

Figure 4.1: Prominent Factors in the Identification Process from the Perspective of Case Coordinators

Excerpts from a range of responses where used below to capture the themes that supported the development of the factors. Please note: (#s) represents the # of seconds.
**Factor One: Previous Records**

The process of identification for children with disabilities requires the review of records at various stages in the referral and evaluation process. Participant responses across questions showed the reliance of individuals and teams on the previous records of children that included medical, prior district/program, and parent/family. The data in the themes illustrated below showcase the case coordinator’s use of previous record information to identify children.

**Theme: Medical**

The use and reliance on medical records from doctors and hospitals was discussed by personnel from each type of school district to include: urban, rural, suburban and small town. The following excerpts showcase some of the experiences across the state of evaluation teams and how they utilize in- and out-of-district resources.

*Researcher: What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?*

Small Town 1: I would want that medical diagnosis at first (laughs), I mean something some specialist has to show me that there's an impairment so if you don't have that then I'm not going to consider it.

*Researcher: You've mentioned services and supports with XXX (regional center name), but when it comes specifically to kids with vision loss and hearing loss there are some services available there, do you think there is a possibility at all that kids are not identified specifically with VI as the primary disability or HI/deafness because of adequacy of resources?*

Rural 1: I really think that VI and HI, maybe not VI as much but HI for sure, medically you get it caught really quick usually and more and more now with screening babies, you know.

*Researcher: Would you say that (poverty level) influences anything for kids with vision and hearing loss?*
Small Town 1: (laughs). This part of Ohio, I've said this before and I got a good tongue-lashing, I call it we're the edge of the black swamp geographically. There's references to the black swamp from the southern edge of what used to be the black swamp which went from here to XXXX (urban northern city). It used to be the edge of Lake Erie that extended down this far anyway I said at some point sometimes we feel like the black hole of services because to get a comprehensive medical diagnosis by a good medical team that specializes in pediatrics we have to go to XXXX (urban city to east) so an hour and a half, XXXXX (urban city farther east) 2 hours, XXXX (urban city to the north) two and a half hours, to get at a children's hospital to get a good workup. And we may be an hour from XXXX (a neighboring state) and I use this analogy but there is a cornfield curtain on the state line because of insurance and services and where we can get services from that we just we may have the services available in XXXX (city in neighboring state) but we can't access them because we're in Ohio. So I don't feel like we have ready-access to some of the specialist that people closer to the urban areas do have. Sometimes that's frustrating. We have a good health department and when I was working with younger students using BCMH to help families with that transportation to at least get that initial diagnosis. It's a good resource to have but a lot of times were just throwing up our hands saying to the families “who do you know? Who do you network with? Who is your family physician? Can we cobble something together (laughs) because were not going to be able, I mean, to rely on somebody else all the time.” Like I was used to doing when I was in XXXX (urban city in neighboring state) for that year. “Oh, we know who to refer you to.” There you just go down the street (laughs).

Researcher: Are there members of the evaluation team that provide information that influences the evaluation team for children with vision and hearing loss?

Urban 1: Yeah they (school nurses) do a pretty good job. They have the hearing test and do all the decibel levels and for vision they do the muscle balance test, they look at near, they look at far. So if some things are shaky they can usually pick something up. They can pick something up. It would be hard to score high and have a significant vision problem

Small Town 2: Obviously if we were to um you know if there's a medical statement you know if they've been to their eye doctor, anything that they can bring to the table that will help us. I mean there are certain standards that you have to fall to fall under you know to qualify under vision or hearing if that, you know, if the medical statement, we don't have anybody that you know besides our nurse who does pretty basic screening of that. When they have that usually we rely on the, on the, on the parent’ doctors too and usually they've been very you know if they have a concern obviously we have that medical statement on hand and that really leads us on what we need to do or where we need to go from there.

Researcher: How do you determine the areas of evaluation in an evaluation team
report? What background information is important to you?

Urban 2: And well the etiology. Yeah, absolutely. Besides the things that have already been mentioned, the medical records, the educational records or outside records. The etiology you know what is happening with the student? Have they uh experience to sensory need from birth or has it been something that's degenerative because that's going to determine different needs in on their journey.

Theme: Prior District/Program

The experiences of case coordinators utilization of information from prior district/program addressed compliance, transient populations, previous disability determinations and younger students was a sub-theme that was most prominent in Urban districts.

Researcher: Could you describe the initial evaluation team meeting including who is involved? And is there a primary person who sees the evaluation through in your district?

Urban 2: Okay, so that is, that can be hard or easy (laughs) depends on how early we can get the information from the last school. So sometimes that's easy and everything is there or the parent is very organized. And then sometimes that takes some time. And once we have the information in hand and usually that's within 30 days then we decide based on those means who we need around the table.

Researcher: What factors would keep you from labeling a student with a loss of vision and hearing as having multiple disabilities (to a specific child in the district)?

Urban 1: We don’t have a lot of kids who start out in our district like that. Most of ours are move-ins. And so a lot of our kids have been at XXX (elementary school in neighboring district with hearing impaired program) when they have those disabilities. Or they have already been at XXXX (elementary school in another district with hearing impaired program). And at that point we trust the judgment of where they were before.

Researcher: How closely does your special education team look at a student’s history when determining whether he/she qualifies for services?

Rural 2: I spend a lot of time in preschool, those kiddos in Help Me Grow usually have some assessment data like the Batelle assessment, they do a nutrition
assessment, vision/hearing, so all that background information. And sometimes will have a speech or OT evaluations as well. So it just kind of depends and at school-age um our reports from children's hospital are usually fantastic.

Researcher: For a child with an initial classification as having deafblindness, what factors could lead to a change in the classification of the child?

Suburban 1: I mean coming in with that particular label, that label meant something to someone. Deafblind. To what extent, to what extent is deafblind? Are there other mitigating circumstances that would say “You know what we could call the student deafblind or are they really multiply-handicapped, is it a multiple disability?” And then you would even more importantly, what difference is it going to make in terms of how we program for that student. Because just because we say “we don't have a program for deafblind students. We have a multiple, we have classes with students with multiple disabilities so we’ll call him that.” No. That's, that's not how it works. That's not how it should work. Has it ever happened that way? Sure I guess it probably has but that's not the way that's not the way you approach it. I think, you know, (4s) can a deaf blind student be learning-disabled? I guess, why not (laughs). Why not. Hey it all boils down to how are you going to the teach student. What strategies are you going to use to teach the student. What it is you are planning on getting out of that educationally. I think that trying to be rigid on, on the identification because it's convenient, that's going to backfire. To me that's going to backfire every time. So it's more important to spend time in that evaluation process and really making this a team, a team decision. Truly, truly understanding and listening to what the parents are saying too.

Theme: Parent/Family

Case coordinators across all four district types expressed the influence of parent/family history and records in the identification process that included the philosophical standpoint of some families in one small town and one urban area.

Researcher: How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?

Rural 3: For initials I have a certain form I try to get parents to complete and for reevals I have a special form that I send out. Initials on almost always get it back, reevals probably like 70% that I get back. Especially for initials I'm looking at that developmental history that um family history, living history.
Small Town 1: What are you willing to share? And sometimes that's an issue. Some of our transient folks would just rather just walk away, that that problem was part of the last school we were at or the last place where we lived. The problem was the last house we lived in and now it's all better. And (laughs) it catches up to them pretty quickly.

Rural 1: Where they’ve lived. Where they live. Where their parents are. Um a lot of it is partially in this district a lot of parents are not involved in their children’s lives. Their children are moving from home to home and we don’t know where they are living at the moment. They don’t know.

Researcher: Please describe the initial referral process including who is involved and what role they play?

Urban 2: Well we have the one case but we definitely knew that they were visually impaired. The issue was the lack of follow through from the home side so we never received any reports based on the fact that they really, truly had significant hearing impairments. Um so once that piece, we had that piece then we were able to make the transition and say “Okay well they’re not just visually impaired identifiable they are actually deafblind.”

Factor Two: Data

Analysis of responses showed case coordinators and evaluation teams focus on data for students to detect and determine disabilities. This emphasis was apparent through the mention of Response to Intervention by various personnel with the most prominent being those in small town and rural areas. These sub-themes included the impact of Response to Intervention, parent/family data and evaluation areas.

Theme: Response to Intervention

Researcher: Please describe the initial referral process including who is involved and what role they play?

Rural 3: The initial referral process um typically those start here at the elementary level. And we have a really solid RTI framework that we so most of those are referrals are teacher-based. So we go through that as a team, the RTI process, documenting the interventions and if they're effective or if they are not effective. And then we kind of determine as a team again if there is a suspicion of a disability. And that would fall to me again to organize the paperwork of who does
what. And if we are doing any related services I’m the one responsible for contacting them and setting that up and giving them the information.

*Researcher*: *How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?*

Suburban 2: We started that planning meeting. We look at whatever data we have on the student be it from our own because we have our own benchmarking data, our high achievement assessments, our classroom performance, um our observations of that student, and we try to come up with the evaluation plan. What is our suspected disability? And then what do we need to do to evaluate that procedurally and to answer questions. I think for most of our kids it’s our trend data that we've gathered from benchmarking, from kindergarten, um.

*Researcher*: *Are there members of the evaluation team that provide information that influences the evaluation team for children with vision and hearing loss?*

Urban 1: Yeah, well if you has a child with a vision and hearing loss, or if that comes in and we already know we are looking a child with a severe vision and/or hearing loss, we would want some real current data on where that is. Are we looking at different categories? Are we looking at blindness or visual impairment? What kind of therapies. It may mean some large print or those kinds of things so you’d want some accurate data. Yeah if it’s a real specific disability like blindness then you know the child probably has some pretty good data.

**Theme: Parent/Family**

All district types acknowledged the role parent’s play in the sharing experiences about their child that included formal response to requested paperwork and observational data used to describe the behavior and functioning level of the student.

*Researcher*: *Could you describe the initial evaluation team meeting including who is involved? And is there a primary person who sees the evaluation through in your district?*

Suburban 2: Typically when we get a request for an evaluation you have to respond within 30 days and so once a parent or a teacher suspect a disability then it usually comes through me or if it comes through a counselor they'll immediately let me know. I get team members together and usually team members include the teachers, intervention specialists, and then the parents and then an administrator and then the school psych. And then any other type of personnel that are pertinent to the team or could give information about it. Parents
are also able to bring in anyone that they would want to like provide more information or anything like that to help them to the process. Yes typically it's the school psychologist who case manages it and that's when they pull in the other team members. So we may even have like an OT or an SLP come in to like the planning meeting and consult with us or to collect more information to get us moving through the process. But yeah typically it's the school psych managing the whole thing.

**Theme: Evaluation Areas**

In the discussion of student the sub-themes of evaluation areas become prominent in participant responses who commented on the role of professionals in evaluating and collecting data to make determinations along with the focus on understanding and assessing student cognition across all district types.

*Researcher: How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?*

Small Town 2: The psychologist when we look at signing consent on what to test she will have had some data that she will be looking at and she very specifically will spell out what she's been testing for. And they just kind of work with the parent at the time the team determines I guess what uh what uh she'll be testing for. There is definitely some very specific things she's going to be testing for in that process and then utilize our related service, our staffing it comes from our related services, and how she needs them what she needs from them. She kind of orchestrates that part of the ETR.

*Researcher: For a child with an initial classification as having deafblindness, what factors could lead to a change in the classification of the child?*

Rural 1: We are probably fortunate in that we know everyone in the district personally. We know who they are. If we need information from a teacher it’s very easy compared to a big district where you know you have to go through multiple channels are you don’t even know who that person is in another building. You know whatever we know everybody. I mean sometimes we even know the grandmas, you know, aunts and uncles, you’ll get information whether you want it or not.

Rural 2: I think of it in terms of an umbrella like mental retardation, you know that there’s such a very profound, severe and then mildly. And I think about that for deafblind as well because you don't really know if you're not using the right
methodology to retrieve what they know. They may not be able to show what they know. So you have to be very careful.

Urban 2: And that's really no different than any other category. I think the point is that with a student who is deafblind you have to make sure that you are looking very carefully at their intellectual abilities and making sure you aren’t making assumptions about their intelligence. And I think we do a good job of that. Yeah. That’s key.

Researcher: What level of vision loss is required to be categorized as having visual impairment? Blindness?

Suburban 1: I think, again I think it gets down to and I believe this with almost all of our assessments too a lot of it is so quantified but when you get right down to it how does it impact the student. I mean I can have, I can have 140 IQ and function like a student with 110 and the issue is it's not that I'm not smart enough it's how are you teaching me. Same way I don't think it's a whole lot different for students with hearing loss, vision loss.

Researcher: When we talk about those two areas, mobility and academics, when does in a spectrum let’s say, when do we start to consider that kid changes from that classification of deafblindness to possibly we need to probably go with multiple disabilities? Let's start with mobility first, does that impact at all for this child?

Small Town 1: I would say that's probably a huge factor. And I would, I'm going to look at service delivery I mean what are we looking at academically. “Do we have intellectual ability?” is going to be huge. What are expected outcomes for this individual? You know are we looking at (sigh) you know ability to learn to do functional academics or no abilities to do that and I would change. That would probably be the biggest factor.

Researcher: What level of hearing loss is required to be categorized as having hearing impairment? Deafness?

Suburban 1: Well again you know I think and I can't speak to this part of it but I think with any of the quantitative measures that you look at and some of the rules and regulations it still boils down to how does this impact you. How is this going to impact you in the general ed classroom? How is this going to impact you being able to get around the school and building and interact with other students? And then we have to sit down as a group and make a determination and decide what that is going to look like. What that program is going to look like. There's a perfect example of one, of one program doesn't fit all, doesn't fit all kids. I mean you go around the school district because you’d initially thought “well why are they in this class?” but they are in there. They’re part of the class, students accept
them, the teacher accepts them, I mean (3s). And if you ask them “well what is that student hearing number-wise?” they’ll say “I don’t know.” (chuckles) Um, yeah, I think, I think we have to keep focusing what it is the student needs and to what extent is it affecting their ability to function within the school environment.

Researcher: How do you resolve disagreement regarding disability categories?

Rural 3: This district more so than any other I’ve worked at is very based on data and numbers which is good and bad. It’s good in eligibility determination because it’s pretty cut and dry a lot of time not just on standardized testing but also on monitoring data that they do here. You know just really noting and plotting out where we want them to be and looking at that and if the numbers aren’t there you know then we aren’t able to qualify. I don’t think we over-qualify, I don’t want it to sound like we’re not providing the services we should, we don’t, they don’t over-identify if that makes sense. Like I said we just share input but it comes down to the, there’s probably been twice, it’s never been where I thought the student shouldn’t qualify, I don’t know how to word this. The times we’ve disagreed the student’s gotten the services so I guess that’s, what is that a false positive, you know where like it’s good they got it even if they didn’t need it. It was kind of, you know it was the administrator’s say and then you’re just okay.

Researcher: Would you say in the time, so you are saying you’ve been in the district (referencing R2) shorter than you’ve been (referencing R1), would you say every year there has been children that come through that have vision loss?

Urban 1: And for severe hearing or vision problems it’s very rare that you are not looking for some cognitive or academic weaknesses because we have not been able to get all the information in a way that can be interpreted.

Researcher: What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?

Urban 1: We would, when we consider multiple disabilities, the main thing we are often looking at is the cognitive factor there um if we are looking at a student with a severe cognitive delay and with a combination of blindness or severe visual impairment, hearing loss. You could look at MD as the overall category and then provide the vision and hearing services. Um that would be the big one. I mean if I had a child who for all the testing you can do the child is totally capable of learning and we definitely are not looking at retardation or anything like that we would certainly not look at MD.
Factor Three: Federal/State Requirements

In the discussion of special education policy and procedures, it would be expected that educational professionals would make some reference to the federal and state requirements that they are responsible for maintaining. The impact of these requirements becomes the third theme in this analysis with sub-themes that focused on SEA tools, definition, funding, IEP-driven determinations, and parent response.

Theme-Tools

The data associated with the tools used to address federal/state requirements had the most frequent mention of tools provided by the SEA to generate discussion related to suspected disability and evaluation.

Researcher: How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?

Rural 3: For deafblind, we we look at uh the checklist from the state department for all of the required areas. And typically if it's done in Ohio because this is an Ohio evaluation then we make sure that everything is there, typically it is. If it's from out-of-state sometimes their criteria is different where we would need to get out the Ohio planning form and make sure that we have all of the areas covered that are required for deafblind. And if they aren't covered in the evaluation then we get permission to add on those required areas. And again sometimes if the team feels that um there's another area that's not required that would be helpful we've done that as well and added people to the team.

Suburban 2: We do use a form that's provided by ODE which actually just goes through each area to look at so typically when we’re talking about disabilities that are suspected we look at what disability out of the educational disability categories and then what information would we need to help with that. So typically were looking at you know do we need cognitive testing, academic testing, are there behavioral concerns. So a lot of times in meetings when we’re talking about the suspected disability we just go through it point by point and talk about is this an area of concern and how would we like to collect information on it.
Researcher: What factors do you consider when determining whether a student should be considered with the label of “deafblindness?” What influences those decisions?

Urban 2: The criteria is clear. The psychologists they want to make sure they are interpreting everything right. That's why it's so important to have the audiologist involved and vision specialist.

Small Town 1: Well we're going to, the medical piece will be huge, and we’re going to look at the operating standards and they took the numbers out I understand (laughs) so we’ve got to look at functionality.

Theme-Definition

As stated in previous research, the definition for deafblindness has been openly criticized for its breadth and the response data showed that most participants were unfamiliar with the actual wording as highlighted by the responses from two rural district personnel.

Researcher: What factors do you consider when determining whether a student should be considered with the label of “deafblindness?” What influences those decisions?

Rural 1: I would say the actual definition provided by the Ohio um operating standards. They have to fit that in order for us to serve them. I haven’t had experience with that but it’s one of the first things I would look at.

Rural 2: You know I definitely always consult my little handy-dandy book (looks for and pulls out book) the rules for students with disabilities. Handy-dandy book (shows and laughs). You know I would take a look at, that's not my expertise area so I would definitely have to rely on this to look at eligibility. (Open book and looks to find definition of deafblind) Wow, that's kind of a gray area (reads definition aloud). Wow, that is kind of intense, isn’t it. I’d look at their visual acuity and I’d be looking at their um audiogram to see where their deafness falls and um compare that to the other and compare that to the hearing impaired and visually impaired definitions and go from there.
Theme-Funding

Case coordinators across rural, suburban and small town districts acknowledged the influence of funding in the identification process. The state weighted-funding formula associated with six levels of funding depending on the disability category were mentioned by some to have influence on decision-making as well as the impact on loss of funds for families in some areas.

Researcher: How closely does your special education team look at a student’s history when determining whether he/she qualifies for services?

Rural 2: Kind of and unfortunately whether this is correct or not this is my perception a lot of times I think a struggling family financially that they understand that they can get SSI so they tend to push a disability and may want that IEP so that they financially benefit. And it's really tough when you're talking about affecting somebody's pocketbook (laughs) they are very passionate about getting their kids identified. And I'm sure it's different in urban areas that that’s not a concern for folks. It is here. It is very hard because again that’s your your perception: you are you, so try not to definitely keep that in mind and just stick to the facts about eligibility but sometimes I think that does cloud judgment a little bit I think.

Researcher: What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?

Suburban 1: Yeah I think sometimes you do run into that not so much from the school standpoint but from a parental standpoint. What I think we always have to look at is I can call you this, I can call you this, but are the services really that different? Just because you have a vision uh a vision um hearing issue and you have, your a student with a learning disability or developmental disability whatever we have here or other health impaired, ultimately what we could be providing there could be some overlapping. Does it really make a difference? Now ultimately it might make a difference in what parents are able to get some funding for on their child.

Researcher: How do you resolve disagreement regarding disability categories?

Rural 2: To me it's not always so much about what category you’re in but how are we going to address the need. To me um you know I’m probably not looking at the same way the superintendent would look at it. You know with a more severe label you are probably going to get more bang for your buck with dollars but you
if you’re LD or OHI are your services really going to be that different? Probably not. So to me it’s not even worth arguing at that point. But if it’s a multiple disabilities versus an autism, sometimes having that autism label will open up more avenues for the parents and the family to get some help at home so.

Small Town 1: And sometimes there's a money piece to that, um, there is a reimbursement if you identify a kid autistic or emotionally disturbed or multiple disabilities but that's never our priority… Usually the data, it's pretty data-driven. I mean if it's in this, that's where we go.

**Theme-IEP-Driven**

The sub-theme of IEP-driven decision making was formed based on the response from personnel from three of the four district types who questioned whether the category mattered if the programming was being offered.

*Researcher: How do you resolve disagreement regarding disability categories?*

Urban 2: It is and more and more we, we realize some students who may fit in more than one category. We don't like to spend an inordinate amount of time reading which categories should they be because it's all about the, the IEP. And it doesn't really matter what that category is if you have needs determined you know from the ETR and other sources.

Small Town 1: Hmmmm (3s) typically we don't have a disagreement because our emphasis is on it just doesn't matter. It's not going to change the services that your child is going to have access to and our day-to-day work in the classroom… And we talk about that and usually the parents if I say “Let's call your kid emotionally disturbed.” I better have a really good reason to do that because nobody likes that label. It's distasteful to say. So (laughs) in the end I'm looking for school-based services it really doesn't matter for us we’ll take the one that makes everybody the most comfortable.

**Theme-Parent Response**

The feelings or stigma that a parent might feel associated with the label of deafblindness became a sub-theme that influenced teams under federal/state regulations in small town, urban and suburban districts.

*Researcher: If there is disagreement do you tend to just facilitate that dialogue?
Small Town 1: Yeah and typically the parent might have some umbrage with a label and I will go with the safer one. I’ll say “Okay it's learning disabilities” instead of you know whatever else it might be. Or you know my kid is diagnosed with attention deficit disorder, okay we'll call it other health impaired, we’ll just not look at (laughs) the more serious things that could move us toward a different label.

Researcher: Let’s go with a parent example. If there are a couple categories a child could fall into, and one has a stigma associated with a category, do you ever deal with that?

Urban 2: And again, if they clearly fit in, could fit into two categories, and a parent just really has a stigma attached to a particular category, as long as they fit the criteria we can go with the other category… we are really kid-oriented and based on needs.

Researcher: What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?

Suburban 1: The spectrum is huge on these kids. Again I think that, we’ll have, we get this probably more from our own teachers than than the people that actually do the evaluation. You know because you're all looking at it from a different perspective and when you do that um the problem (chuckles) the problem I can say “yeah we’re going to identify you as deafblind” and it may be after the teachers have been meeting with the parents and meeting with the student and talking they may say “yeah you can call him that but he's doing really well do we really need to call him deafblind because that appears to be much more severe than if we call him something else.” I think there is room I think there is wiggle room on that because on every disability even though it's black-and-white when you make that identification from a realistic standpoint there's deafblind, deafblind, deafblind, deafblind, deafblind (using hands to illustrate different points) you know the mildest vision, vision issue with a hearing loss, I guess at what point do you say this was deafblind versus something else. And to be honest with you I'm sure the, I can't tell you the criteria for a student identified as deafblind because I can't remember the last time we really had to deal with that.

**Factor Four: Evaluation Team Members**

The largest amount of data across all fourteen participants in each of the nine districts had to do with evaluation team members. Sub-themes in this area addressed the
role of the administrator, teachers, related service personnel, parents, outside agencies and the experience/resources in the district.

Theme-Administrator Role

In the discussion of evaluation team members, the role of administrators showed to be influential across all four school district types. Personnel in a variety of roles discussed the concept of team decision-making but the majority acknowledged that administrator’s input can override the team and influence the label.

*Researcher:* What is your position within the district, and how does that position relate to your role as a member of the special education evaluation team?

*Small Town 1:* Alright, first off I'm a school psychologist that's my training. In this district in XXXX (school district name) I am also the special education coordinator for grades six through 12. I don't have any certificates in administration (chuckles) or special education coordination but this isn't the first time I've done it either so. On the evaluation team as a school psychologist I’m the gatekeeper.

*Researcher:* How much influence do you have on the special education evaluation team’s decision-making process?

*Rural 2:* If I’m the district rep on that team unfortunately my decision kind of trumps (laughs). Yes. Whoever the district rep is that's who usually, I mean it's a team decision, last say is the district rep.

*Rural 3:* I would say I have a decent, we really strive to make sure it's a team, but it's hard because not everybody comes in the same knowledge of the law, knowledge of the student to make that decision so you really want to make sure your evaluation is comprehensive and complete to try to give them that picture by the end of the meeting. I would say I have, it’s team decision but my input is valued if that makes sense. It has some weight to it. I think it depends too on the building because we have three administrators, principals I should say, and one superintendent. And I would say they all play a varying role depending on their own level of interest and knowledge. The high school principal, he doesn't take very much interest, he's comfortable leaving it up to the service providers to make that decision. The elementary school principal and to some extent the middle school principal are very influential. (3s) their input is valued the most. Their decision is the one that typically this is what we are going with.
Urban 1: Yeah, we are a team. (laughs) We don’t get to override anybody.

Urban 2: From where I sit I make sure that we are in compliance. So the team makes a decision, that's regulation, so I'm making sure that they've got all the required pieces and place for that exceptionally. Um, yeah, the team makes the decision they know, they make the decision on the best classification for the child at that time. So from where I sit I'm just make making sure we follow the requirements. I’m not typically at any of those meetings.

Theme-Teachers

The role of teachers on the evaluation team was offered by rural, small town, suburban and urban districts where data highlighted the impact on referral and service delivery.

Researcher: Please describe the initial referral process including who is involved and what role they play?

Rural 1: You know because we have some teachers that automatically just want to refer. And then we have other teachers who are just very cautious and probably don’t refer until well probably they should have referred months ago… we’ll draw the teacher in to talk about the initial referral but like I said before we vet it to make sure it’s valid that intervention is tried and that things have gone on to follow-through. But we are the team, in a small district like this. There just aren’t other people.

Researcher: Could you describe the initial evaluation team meeting including who is involved? And is there a primary person who sees the evaluation through in your district?

Small town 1: I want my intervention specialist to be the first point of contact. I want them to have the relationship with the family. I want them to, you know, be the people the mother calls at 9 o'clock at night “you know I'm really frustrated about whatever” and that they have that relationship. You know I don't ever expect that but it happens in this community.

Researcher: How much influence do you have on the special education evaluation team’s decision-making process?

Urban 2: I think I do have some influence because if I know that they qualify visually impaired but they might not standalone qualify as hearing-impaired knowing what the definition is, if they have any type of hearing loss whatsoever, and they’re qualifying for the vision then they qualify for being deafblind. So I do
know that. So therefore if that came up to the team, well the hearings not really affecting because is not significant enough to be identified as hearing-impaired, well according to the law we know that it is because that changes the category.

**Theme-Related Services**

In the discussion of evaluation teams, school districts in rural and urban areas suggested the importance of speech and language pathologist on the team. One suburban district offered the role of audiologists in planning along with one urban district that also has a teacher of the visually impaired on staff.

*Researcher: Could you describe the initial evaluation team meeting including who is involved? And is there a primary person who sees the evaluation through in your district?*

**Urban 2:** I would say for these students because most of them identified very young then we make sure that whatever that team um you know the team that was involved on on the early childhood programming they are a part of the team at the transition meeting. And that's where all the information is shared and we have a, we have two preschool psychologist, and so they then put together who is needed, who makes sense to be on the team. In the case of a student who is deafblind it would definitely be a speech and language therapists.

**Rural 3:** I'm the one who pulls it all together, makes all the copies, and I lead the meeting. At the meeting typically we’ll have obviously the general ed teacher, we’ll have an intervention specialists at the meeting primarily for the results, they are not involved up until that point. They don't provide any of the interventions up until prior to if it’s an initial. But they'll come to hear the results and help with that eligibility discussion. If we have any related services, typically with an initial I would say typically always at least do speech and language testing just to rule it out. Again they are employed through the ESC but they are housed here on a consistent basis. OTs and PTs are only district one day week based on our population. So we don't refer for that testing unless there really is a suspicion. So the intervention specialists, the gen ed teacher, myself, parents. We usually have pretty consistent parent attendance here so that's good especially for initials, I don't think I’ve ever had a parent not come for an initial (laughs). So parents and then if there is any related. Principal, gen ed, special ed, me, parent, speech and language typically.

*Researcher: Are there members of the evaluation team that provide information that influences the evaluation team for children with vision and hearing loss?*
Urban 2: And audiologists I would say would be the other one in the case of deafblind to make sure that we have those people there. Those are the two key people (audiologist and TVI) in determining. Yeah, in determining, they know the most about that.

Theme-Parent

Responses from district personnel on evaluation team members showed the impact of parents on areas of evaluation and disability determinations across suburban, small town and rural areas.

Researcher: How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?

Suburban 2: Sometimes we see differences between home and school so a parent can really provide us with more information about things to look at.

Suburban 2: And I think that's especially helpful when you have students who have not been in our district the entire time. You know by high school we have some students who we may be their ninth school so trying to track records from that many places is pretty much impossible. So getting parents here sometimes help at least connect the dots.

Researcher: How do you resolve disagreement regarding disability categories?

Small Town 2: Now we've had disagreements with parents sometimes on what they feel their child would qualify for um but with our team, collaboration, we will bounce things and have conversations with each other. I have a lot of regard for what uh hold in high regard what my psychs usually when they come to me and ask, they’re asking my opinion I will, they will lay it out and I will ask them what their opinion is.

Researcher: What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?

Rural 3: So I mean if it was deafblind, and again I’m not sure how you, not interacting or evaluating that population, I’m not sure how you determine if there’s cognitive needs or if there’s you know adaptive needs once um you know so kind of trying to piece all that out. That’s how I’ve always done it is try to figure out what, what do I think is the reason, what is hindering this student from making or getting their needs met. I think another big factor is parents too. I mean where is their comfort level. I mean a lot of times and I guess I should have
addressed that earlier when it goes down to team decision, I said administrator but I mean parents ultimately have that right and that call.

Theme-Outside Agencies

A very consistent topic across district types was the use of outside agencies in the evaluation process. Responses showed membership from outside agencies that included regional centers, state support teams, caseworkers, therapists and medical professionals.

Researcher: Could you describe the initial evaluation team meeting including who is involved? And is there a primary person who sees the evaluation through in your district?

Suburban 2: Like sometimes if there is caseworkers involved they might come in and give more information. Sometimes therapist come in. We a lot of times they bring in doctors.

Researcher: How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?

Suburban 1: What we will do is contact the regional center um because that's part of what their part of what their job is to sort of keep up to date with some of the agencies that are out there and um who's doing what, is there a new clinic in town, is there a specialist that we've never used or that they've used. We would typically start with them. If we run into you know a proverbial brick wall that's when I or our psychologist or coordinator would call people in XXXX (city name) and at XXX (SEA) and say okay could you give us any direction on this. Sometimes they can, sometimes they can't depending on who you get to at XXX (SEA) which is not all the time easy. Often times though what I will do, I will call my colleagues in this whole area, we have um we have a group um student services directors or in some cases it might be just the special ed director who does only that piece and we meet every month or so we become you know we know each other and it covers pretty much three different counties around here and if need be I just get out my list and start calling and say “okay I’m needing someone” send out a group email to everybody and say “look you know we are going to need to evaluate a student in this particular area uh have you had this? where have you gone? What have you used?” and that is is not unusual for us to do that. I should say that differently, it wouldn't be unusual for us to do that. In most cases evaluations that we do would not fall into that category it's a little bit more complex than most of our psychologists would be trained in I think.

Researcher: Are there members of the evaluation team that provide information that influences the evaluation team for children with vision and hearing loss?
Suburban 1: Well I think, I think on any evaluation team there is going to be heavy responsibility on the part of the school psychologist. People are going to look at them as the experts, the experts in the field but in doing so if we are looking at something like vision, hearing or even a combination we would've brought in other other um experts in the field. So we do have consultants out of our regional center in vision and in hearing, orientation and mobility and all other sorts of things that we would make part of the team. Um when it gets when you really get down to talking about the disability we rely great deal on them, again most of the time we agree, sometimes we say “we’re not really seeing that let’s talk about this more”. We do use them a lot.

Researcher: Can I go to those two examples you gave? The student at XXXX (school name for children with autism in another district) you said, so classification-wise um I’d say had the classification may have started and when did it change or did it start the same and maintained?

Urban 1: She had moved to us and I believe it was um, I’m thinking she was an MD. And then we’ve got the blind coming with the Usher. We’ve got all these other things happening. Then we’ve got the autism diagnosis coming from the specialist. This was a complicated, one of those things where what do you okay what do we serve? Okay for our little lady we have autism, we have deaf, and we have near-blind so we’ve got a very complicated young person. She got that label (autism) two years ago through some, a behavior clinic and the parents were seeing, even with the other, acting, very strange behavior. And you know it’s hard to sometimes separate what is there because with the fear that’s happening to your body you are also a little, there were some cognitive impairment, it’s real hard.

Theme-Experience and Resources

The sub-theme of experiences of personnel and resources received a large response from case coordinators across every aspect of the evaluation process. A high level of educational experience, average of 20 years, was reported across participants with the majority having a low level of experience and comfort with the disability area of deafblindness with a heavy reliance on other professionals to meet the needs of students in the district.

Researcher: Are there members of the evaluation team that provide information that influences the evaluation team for children with vision and hearing loss?
Rural 1: My background knowing who they are and having been here for so long that I know who we can access. Where as XX (school psychologist and co-interviewee) has only been here two years, and she’s learned a lot, but I know even the specific person to call because we are so small and rural. So we make that contact um and having been a part of that team in the region that is helpful. You know unfortunately some districts don’t have that intimate you know knowledge and I think that affects some of our small, rural districts. Accessing that information.

Rural 1: I mean you know that exact person to talk to where as if it was just me here on my own I would probably be doing a google search or something. I mean that is how I would try to get my information and um that is not always the most accurate and up-to-date information.

Researcher: Do you have the resources to evaluate and educate students with deafblindness in your district currently?

Urban 1: We have the resources for mild. Not for intensive.

Urban 1: Total blind it depends on the severity. Real, real severe and then you’re also there’s also often times more we’re talking some of the kids might be cognitively impaired also. Physical. There might be a lot of other things going on. If you are looking at real severe we probably don’t. We could try it but it probably wouldn’t be (2s) the most effective for the child. I think we are kind of limited. And when you’re with that population you really need to be with individuals where that is their area of specialty.

Rural 1: Where we are. Who wants to move to XXXX (city name) if you are not a country person? Economics. This district is one of the lowest paying districts around. Um so if you move here where is the housing? I mean it’s an economic issue about getting people here, the lifestyle.

Researcher: What has been your experience in classifying a child with more than one disability that includes vision and hearing loss?

Urban 1: No there are some things that are becoming more pronounced (3s), like autism. We have some with hearing aids and the cochlear implants that are here and are doing well. Severe we are usually looking at school for the deaf or XXX (hearing impaired program in another district). And for severe vision we would always be looking at school for the blind or something there too.

Urban 2: I mean our our very severe students um I believe have a hearing and vision issues but have very severe intellectual disabilities as well. Those students are not here they are in a different facility. And I believe, their primary category would be more like multiple disabilities.
Researcher: What is your level of comfort in addressing the needs of a child with deafblindness?

Urban 2: I’m pretty comfortable with the students that I serve. You know I don’t have or we don’t have any students that are in general ed that are totally deaf. Now if we had a student that was totally deaf I would be uncomfortable until I learned how to communicate, you know, but we don’t have that. The kids are you know they have their hearing aides as long as they have their hearing aides and their batteries are functioning and everything is the way it should be and they have their FM systems and we are able to communicate than we are fine. If a student moved in tomorrow that was totally deaf than my comfort level would not be what it is now. Your data changes from one day to the next but right now I’m at a 10 (laughs). Beginning of January I could be at a 3 (laughs).

Urban 2: I was going to say a 9 because we are fortunate being a small urban district and to have a lot of resources available. So it’s a matter of understanding the criteria for the categories that you are looking at, and if you don’t think you have enough information, then you find the specialist that you need to add to the team. And I feel like we always do that so I would say a 9. I was going to say I would say a 9 most often. We always have everyone that we need. Maybe small rural districts, they probably struggle with that.

Researcher: For a child with an initial classification as having deafblindness, what factors could lead to a change in the classification of the child?

Urban 1: A moderate hearing loss um probably not. She would be hearing impaired with blindness but she’s pretty severe. She hears very little and it’s probably the broken kind that I get a sense for the sound but part of the word is missing and then I get another sound. So it’s hard to comprehend what that sound was. That’s a real complex, complex situation.

Rural 3: I would think, again not working with this population, like how you know like deafblind what if they get a cochlear. You know what I mean? I’m looking at that kind of thing um I could see that maybe. Again not knowing the definition or this population very well. I would say maybe something like that. I don’t know what medically what kinds of things can be done for somebody that is deafblind. What can be done? I know about the cochlears or something like that. Like I said if we are looking at their progress and there is none. But I wouldn’t really see, even if a student with deafblind, and we’re educating here in the unit with the students with multiple disabilities I mean that’s what we call it the unit for students with multiple disabilities. Not all of those students have that label. I think it just goes back, the label is trying to give you as um as um a service provider an idea of what those needs are but the bigger meat of the issue is how we’re meeting those needs.
Researcher: What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?

Urban 1: I think in a lot of places you have more expectations for a child who is deaf or visually impaired than you do for an MD child. When I get IEPs coming in and the child is MD I automatically figure that there is probably a cognitive deficit there.

Rural 2: I guess for me not having the experience and I've been in the field for 26 years. I didn't have any students labeled deafblind either when I was the classroom so (5s) and I just think it’s more difficult. In this area we know less about instructionally for servicing those kids. For those more intense needs.

Researcher: So when I say someone with deafblindness, in your mind, how does that person communicate?

Rural 3: I have no idea. I probably sound like really (3s) I don’t want to sound stupid (laughs) but you know like I obviously think of Helen Keller. Very intelligent woman and just trying to find out how you can crack that code for that child, that person and find a way. It’s a good thing we have some good speech therapists and people to help communicate. I mean what did she do, a lot of stuff through feel and tactile. So I um I’m not sure. I’d love to learn and really depend on resources and other professionals to hopefully help us.

**Factor Five: Referral Sources**

The fifth theme in responses from case coordinators from urban, suburban, small town and rural district addressed the referral sources and how they impact the identification process. Included in the area are three sub-themes that showed prominence in responses: medical, parent, and EI/preschool.

**Theme-Medical**

Interview responses across questions and districts highlighted the role of medical professionals in the identification process. This role in the area of education begins with the referral.

Researcher: Please describe the initial referral process including who is involved and what role they play?
Suburban 2: Initial referrals can come from anyone so it can come from parents, teachers, or a lot of students who particularly for students who have to deafblindness it'll come from the doctor.

Researcher: Could you describe the initial evaluation team meeting including who is involved? And is there a primary person who sees the evaluation through in your district?

Suburban 1: We get information from like Children's Hospital in XXXX (city name-urban west) or Children's Hospital in XXXXX (city name-urban south) will get referrals, perhaps a call from like the school for the blind or the school for the deaf, where you have a student that they are at least aware of and a parent has gone to them before they've even come to the school district.

Theme-Parent

School district personnel in rural districts noted the role that parents play in the referral process more than any other district type.

Researcher: How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?

Rural 2: But so as we’re talking to the parents, or Help Me Grow is involved or Head Start, you know at the preschool level we have seen different agencies involved um but typically they will say “Oh we have concerns with fine motor.” Or have concerns with sensory so really we kind of let the parent and the agency guide that discussion because they are obviously know the child better than we do.

Researcher: What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?

Rural 1: Older. Probably middle school when they don’t want to be different than other kids….Another one and he has amblyopia as an eleventh, no tenth grader, um was supposed to wear a patch. You know help him, give him visual supports, and the family didn't make him do it. He didn’t care. It’s a different culture of family and so he didn’t do it and now he doesn’t have any vision in one eye. Um, whatever we offer it doesn’t matter. They don’t care.

Theme-Early Intervention/Preschool
Case coordinator response from all four-district types showed a belief that children with deafblindness are being identified at an earlier age due to district or community programming.

Researcher: Please describe the initial referral process including who is involved and what role they play?

Urban 2: Well as in regards to deafblind because it's a little bit different for student who is deafblind I cannot think of a case where it hasn't come from, where they haven't been identified early on through early childhood. And so then it's a matter from transitioning to uh the early childhood program to school age or preschool and then we make sure that we have a transition conference. We do any additional assessments we feel that need to be completed and then we discuss programming and what’s going to be best. Make sure that we have supports and services in place based on the IEP. I can't think of anywhere we haven't known ahead of time, a student with, a student that would fall into that category they are usually identified quite young.

Researcher: Could you describe the initial evaluation team meeting including who is involved? And is there a primary person who sees the evaluation through in your district?

Suburban 1: Within the schools say, there wouldn't be a chance, while there's always a chance, the student that is deafblind we are going to know about that student. From our preschool through uh other kinds of agencies calling us to say there's a student moving into your district that's pretty much goes.

Researcher: What has been your experience in classifying a child with more than one disability that includes vision and hearing loss?

Urban 1: And I think there is more of an increase at the younger age now because I have probably 7 or 8 kids that are either vision impaired or hearing impaired. But they’ve all come through our preschool. So I think just the fact that we are identifying kids younger, we are getting them, because we don’t have a lot at an older age. And hearing impaired kids tend, almost everyone has something else going on that’s tagged on.

Factors within the Stages of Identification
It has been determined that the themes and factors described have influences within the process of identification. To better understand where the relationships lie across factors within the process of identification, the content (e.g., questions, responses) was grouped into one of four stages that included: pre-referral, referral, evaluation and Individualized Education Program (IEP) as illustrated in Figure 4.2 

*Factor Prominence Across Stages of Identification.* The radar chart highlights the responses from case coordinators related to the research question and shows the influence of all factors within the districts represented across each of the stages of identification. Most importantly, in response to the question, it shows that all five factors have the strongest relationship associated with the stage of referral more than any other stage in the process of the identification for children who are deafblind.

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**Figure 4.2: Factor Prominence Across Stages of Identification**
Additionally, the following radar charts (Figures 4.3-4.6) illustrate a breakdown by district typology to showcase relationships among the factors identified within each of the four stages of identification discussed.

Figure 4.3: *Relationships Between Factors within the Stages of the Identification Process in Rural Settings*
Figure 4.4: Relationships Between Factors within the Stages of the Identification Process in Urban Settings

Figure 4.5: Relationships Between Factors within the Stages of the Identification Process in Suburban Settings
In addition to the stage of referral, across each of the districts, the charts illustrate the moderate to strong relationship the factors have on the stage of evaluation and the influence of evaluation team members within each of the different typologies. The weakest relationships associated with the factors can be seen across each of the districts within the stage of pre-referral but data suggests that the influence of current methods to better support this stage are currently in development in a number of the districts represented to address the educational needs of students using instructional interventions.

Previous research in the area of identification in the field of deafblind showed evaluation team members, federal/state requirements, and previous records as factors that influence the identification process for children who are deafblind. This study suggests that from the perspective of case coordinators two
additional factors, performance data and referral sources, also influence the process. Although the strength of the relationship of evaluation team members is evident across districts, participant responses suggest that federal/state requirement continue to guide educational team planning.

**Chapter Summary**

The data collection process to complete this exploratory study included interviews with fourteen participants, case coordinators and/or additional evaluation team members, across nine districts. Participants across urban, suburban, small town and rural districts responded to questions regarding their experiences through the stages of the identification process in the area of deafblindness for students. Responses showed a range of experiences and resources utilized across the state that influence the identification process with each of the five factors have varying degrees of strength across the stages with the biggest strength across all five factors associated with the stage of referral.
Chapter 5: Conclusions

Introduction

The purpose of this dissertation was to begin an exploratory study using qualitative methods that examined the factors that contribute to the underidentification of children with deafblindness through child count data in a large, midwestern state. Existing research on the topic of identification for children with deafblindness has primarily focused on the perspectives of service providers in the field who work with state deafblind projects. As these individuals offer many insights into the reasons they believe children are under-identified as having deafblindness, or misidentified under another disability category (e.g., visually impaired, multiple disabilities), a broader perspective from additional educational professionals is needed to more accurately understand the issues associated with the process. For this reason, the experiences and perspectives of case coordinators that coordinate and evaluate children for special education services in local school districts and determine disability classifications were examined.

Overall, the perspectives of these individuals guided the development of theory on the part of the research team in response to the research question that suggests:
From the perspective of case coordinators, the five factors highlighted have the greatest influence on the referral stage of the identification process for children who are deafblind.

The findings and interpretations of the research will be discussed in the following across all five factors: previous records, data, federal/state requirements, evaluation team members, and referral sources.

**Previous Records**

Research in the area of identification for children with deafblindness has historically not had reference to the influence of previous child-specific records on the process. This study showed that a heavy focus on this newly identified factor based on the responses of participants across every step of the evaluation process from referral to disability determination. Participants across every school district type acknowledged their reliance on medical, prior district/program, and parent/family records in the identification of children. Of the stages, respondents stated that evaluation teams were most frequently using previous records to determine the areas of evaluation and if a student qualifies service. Urban and small town district personnel shared that it has been their experience that medical records specifically have influenced the evaluation team for children with vision and hearing loss.

Contradictory responses from a small town and rural district suggest that area of residence or where a child is born around the state influences identification based on the existence or lack of medical services. The responses from one urban and suburban respondent also suggest a pre-existing label of deafblindness may or may not be re-examined depending on evaluation team opinion. The urban district shared that they have
maintained the label of deafblindness for a children coming into the district reasoning that the child with hearing loss came from a program they could trust. The team member from one suburban district questions when considering a change in classification for a child with deafblindness to \textit{multiple disabilities} if the label made a difference when programming was in place.

Across all four district types the influence of parent/family records played an influential role in the determination of disabilities. Parent feedback at initial evaluation meetings, living history, as well as level of follow-through for service delivery impacted the time to complete the evaluation process.

\textbf{Data}

Feedback collected from participants showed emphasized an increased effort across districts to employ methods that support the use of Response to Intervention to gauge student performance. In this area of discussion the only district to make the distinction between high and low incidence disabilities for interventions was a participant from a small town district who acknowledged that the process would be different for students with low incidence disabilities.

Across all four school district types a reliance on the feedback from requested paperwork and observational data from parents was evident and used by the evaluation team at various stages of the identification process. One prominent theme under the factor of data included evaluation areas that were carried out by team members. The role of the school psychologist in the classification process as a case manager and evaluator was evident across urban, suburban, rural and small town districts which can be
compared with a limited level of comfort on their part regarding the disability of
deafblindness as reported by the school psychologists interviewed.

The tools used for the assessment of students with deafblindness have been more
recently researched by Rowland, Stillman and Mar (2010), who found that there were not
any universally accepted instruments to address cognition, communication and learning
styles. Suggested reasons for this disconnect showed a lack of awareness and access to
tools that are appropriate for deafblind children among professionals. All participants in
this study support that finding by reporting that they did not have resources in the district
to evaluate students with deafblindness with three stating that they would plan to contract
with the regional center in the area. This suggests that the experiences of student
identification may be impacted by a lack of resource to adequately assess cognition,
communication and learning styles for student across the state.

**Federal/State Requirements**

Previous research from the field of deafblindness in the area of child identification
most frequently suggests that themes from federal/state requirements play a large role in
the discrepancy between child count numbers. For this study, the themes determined
included: tools, definition, funding, IEP-driven determinations, and parent response.
Every participant cited disability-specific information from documents offered by the
state department of education that provides direction through the evaluation process with
the use of tools and language in guidance documents. These tools offer district staff
considerations for evaluation for students based on disability classifications determined
by the team. As suggested by previous research the problem with this method is that
many students could be considered misclassified. This supports the findings of Baldwin
(1992) in previous research who shared that state administrators acknowledged that students with deafblindness were labeled with other disabilities (e.g., multiple disabilities) due to district placement options or the lack of professionals with the appropriate licenses or training to meet their learning needs.

Data collected in this study suggest that compliance concerns still exist but are not driven by programing options for deafblind students in settings traditionally serving student with multiple disabilities. Personnel from all four district types suggested classrooms with students with multiple disabilities could be an appropriate placement option for students with no acknowledgement of licensure requirements as suggested in Baldwin’s study. A more frequently stated theme included the influence of parent response to state language and the incidence of case coordinators questioning the importance of a label if the student is going to receive services from the IEP anyway.

In regards to the definitions, every participant stated that they would have to refer to guidance documents offered to see what the definition of visual impairment or hearing impairment would be and each expressed low level of comfort in regards to meeting the needs of students with deafblindness.

**Evaluation Team Members**

The largest amount of data across all fourteen participants in each of the nine districts had to do with evaluation team members. Sub-themes in this area addressed the role of the administrator, teachers, related service personnel, parents, outside agencies and the experience/resources in the district. Although the concept of team decision-making was suggested by participants across the four school district types, the role
administrators often play as district representatives holds weight when it comes to decision making as stated by personnel in every district except the two urban areas.

This level of administrator involvement suggests variation across districts and in different setting with a heavier reliance on additional personnel in many districts to address student needs to meet compliance requirements. Responses to the level of teacher involvement also showed a difference across rural, small town and urban districts. One small town administrator relied on intervention specialist to be the primary linkage to the district while an urban case coordinator brought a teacher for the visually impaired to the interview because they are the constant contact for all children with vision loss in the district. Previous research in the field suggests that a factor influencing the discrepancy in child count data is related to children being labeled as having multiple disabilities due to misconceptions of the evaluation team. Muller (2006) addresses this discrepancy by stating that since the majority of children with deafblindness do have additional disabilities, they are not included in the FCC as deafblind.

These misconceptions could be due to the general public’s understanding of the disability. The socially constructed conceptions of deafblindness have no doubt been impacted by the legacy of Helen Keller, who had profound losses in each area. Contradictory to this specific perception of deafblindness, Fredericks and Baldwin (1987) state that approximately ninety four percent of children identified through the National Child Count of Children and Youth who are Deafblind have some usable vision or hearing, which is a statistic that has stayed consistent over time. Both suggestions from previous research for the factor of evaluation teams continues to hold true based on participant response in this study and are guided by the members of the team that include
most frequently administrators, school psychologists, teachers and parents. Suggested influence on the evaluation team was given to administrators, parents, related service personnel and school psychologist.

In the discussion of themes associated with the factor of evaluation team members all district types acknowledged the request for assistance from outside agencies. A difference was noted in the district-request coming from personnel in suburban, rural and small town districts and the agency participation being parent-initiated in the urban setting. This could suggest that urban administrators have fewer concerns related to their district personnel’s ability to address the needs of the population. A high level of educational experience, average of 20 years, was reported across participants with the majority having a low level of experience and comfort with the disability area of deafblindness, especially as the severity of the vision and hearing loss.

**Referral Sources**

The themes associated with referral sources suggest that medical professionals, parents/families and EI/ preschool programming most frequently influence the referral process in the experiences of case coordinators. Suburban districts reported the referral of children with deafblindness from the medical community more often than other district types who most frequently reported referrals from teachers and parents. Early intervention and preschool referrals have increased over time across districts for children with deafblindness while two of the rural district participants mentioned the decision to not accept special education supports by families as children aged. No previous research focuses on age as a factor for identification of children but research does exist to show
that children with hearing loss are being identified more frequently than those with vision loss due to newborn screening processes.

**Limitation of the Study**

The limitations of this study include the lack of previous research in the area of identification for students with deafblindness, the number of participant perspectives generated, and the range of participant experiences examined. Although findings from previous research related to the over- and under-identification of children across disability categories other than deafblindness were included in the review of literature, and considered in the development of the methodology for this study, a solid foundation does not exist for the specific population. The attempt to complete an exploratory study was dictated by lack of research limiting the amount of focus and depth on the factors examined.

The number of participant perspectives generated were limited by the amount of districts that had identified children with deafblindness in the given academic year, as well as, by the number that were able to participate in the study. As mentioned prior there were twelve districts invited to participate with only personnel from nine districts able or willing to meet to complete the onsite interview for the purpose of data collection. Of the nine almost half the case coordinators unexpectedly invited additional personnel to participate. The benefit of this action led to the collection of accounts for an additional five participants that were not originally planned but it also led to an inequitable number of responses that might have allowed for a better comparison of data across districts.
Implications and Recommendations for Future Research

This study examined the identification process for children with deafblindness from the perspectives of case coordinators in one large, midwestern state. As a result, several questions have emerged that would benefit the field of education in closer examination through further investigation. Suggested next steps include the use of targeted sampling to more thoroughly examine the themes of the current study, investigation of the experiences of school psychologist, early childhood and regional personnel that influence each of the stages in the process of identification, and the use of similar methods to explore current concerns related to over- and under-identification across other disability categories.

The lingering question that has been asked from the conception of this study has been, “Does it really matter how children are identified?” and through responses from the current study we see that educators in the field wonder the same thing as they are making determinations that impact children. As a researcher, when we consider the notion of social justice, it is important to think about why a phenomenon is occurring for a specific group. Currently in our country the support services and specialized instruction required for some of our most vulnerable students is determined through the policy-driven law in the area of special education. These rules and regulations have been developed to better meet the needs of specific populations of students who are quantified by the use of child count data. This data helps to dictate the use of funds to support educational planning, personal preparation programs and evidence-based research to improve student performance. In response I say that understanding the needs of a population really do matter so that policy makers and educators can best support the learning needs of students
by providing a *free and appropriate public education* in our existing structure which is dictated and driven by federal legislation.
References


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(***denotes references not cited in text, used for reference only)**
Appendix A: Sample Letter
Appendix A: Sample Letter

Eastmont City Schools  
May Smith, Special Education Director  
123 E. Main Street  
Mentor, Ohio 44071  

August 20, 2014  

Ms. Smith,  

My name is Heather Herbster and I am a doctoral student at The Ohio State University in the area of education. Currently, I am in the process of completing research on the evaluation of children with sensory disabilities for eligibility for special education services and disability classification. I would like to invite you to participate in my dissertation study, *Special Education Eligibility and the Category of Deafblindness: Examining the Perspectives of Case Coordinators*, due to the administrative role you play in the district. All invitees represent districts that reported as having children with *deafblindness* in the 2012-13 EMIS child count. In the attached document you will find information about the purpose of this research that is designed to address the following research question:  

*From the perspective of case coordinators (e.g., special education coordinators, school psychologists) what factors (e.g., medical, educational, social) influence the identification process for children who are deafblind?*  

The intent of this study is to gain a greater understanding of the practice of evaluation and classification for children with sensory loss. This letter is the initial step in securing your participation. You will receive a follow-up phone call in two-weeks from the date of this letter to discuss participation from your district. At this time you will be asked again to participate or offer contact information (e.g, phone number and email address) for a district designee that is either a special education administrator or school psychologists that would represent the role of *case coordinator*. If you have questions in the meantime, please contact Dr. Peter Paul, Principal Investigator, at paul.3@osu.edu or Heather Herbster, research staff at Herbster@wowway.com or (614) 602-7998.  

Thank you for your time,  

Heather Herbster  
OSU Ph.D. Candidate
Appendix B: Informed Consent
Appendix B: Informed Consent

- **Subject rights:** Participation is voluntary and all participants have the right to withdrawal at any time without penalty. Participants also have the right to skip any question they feel uncomfortable answering during the interview process.

- **Purpose of the study:** You are being asked to participate in this exploratory study because of the role you play in the district as a special education administrator. Your district was selected using 2012-13 EMIS data that indicated there was a child with deafblindness that was reported. The purpose of this study is to gain a greater understanding of the initial evaluation procedures to determine the disability classification for children with sensory loss which have not been investigated from the perspectives of special education case coordinators (e.g., directors, coordinators, school psychologists) through previous research.

- **Study procedures:** This study involves completing interviews with designated case coordinators in school districts that have been selected. Information from these interviews will be collected using audio-recordings, or using handwritten notes when preferred and requested, with field notes that will then be analyzed by a small group of researchers. This information will then be shared as part of the dissertation process. If you agree to participate you will be asked to take part in a one-hour interview in a private room (e.g., local library). Following the completion of the interview, you will also be asked to submit a letter of support on district letterhead that can be included as part of the research records.

- **Confidentiality:** The information collected will be used for research purposes only. The data will be kept confidential using encrypted files that will be destroyed following when the final analysis is completed and presented. Results of the study may be published in an academic journal and as a conference paper and may include narrative from the interviews but all identifiable information will be removed.

- **Contacts and Questions:** As previously stated, the intent of this study is to gain a greater understanding of the practice of evaluation for children with sensory loss. Guidelines to eliminate risk have been followed in designing this study with final authorization being granted by The Ohio State University, Office of Research. For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact Ms. Sandra Meadows in the Office of Responsible Research Practices at 1-800-678-6251. If you have any questions about this research, please contact Dr. Peter Paul, Principal Investigator at paul3@osu.edu or Heather Herbster as research staff at 614-602-7998.

______________________________
Participant Signature
Appendix C: Follow-Up Telephone Transcript to Administrators to Determine Case Coordinator
Appendix C: Follow-Up Telephone Transcript to Administrators to Determine Case Coordinator

Hello, I am Heather Herbster, a graduate student from The Ohio State University calling in follow-up to an email that was sent on XXXXX (administrator). May I please speak with XXXXX?

| When desired person gets on the phone | Hello (Mr./Ms.) XXXXX. My name is Heather Herbster and I am a graduate student from The Ohio State University. I’m calling in follow-up to a letter I sent to your attention on XXXXX in reference to my dissertation research study entitled, *Special Education Eligibility and the Category of Deafblindness: Examining the Perspectives of Case Coordinators.* Your district was selected from EMIS (Education Management Information System) data reported in the 2012-13 school year as being a district with a child with deafblindness enrolled. As a graduate student in the process of completing my dissertation research, I am using this data to complete face-to-face interviews with designated case coordinators (e.g., special education directors, school psychologists) who work as part of special education evaluation teams to make disability determinations for students who have been referred with vision and hearing loss. This study will not ask for/or reference individual children but is intended to address overall district procedures. The purpose of the study is to gain a greater understanding of factors that influence the identification process for children who are deafblind from the perspective of professionals from outside of the field of deafblindness (e.g., special education case coordinators-special education directors, school psychologists). |

110
because there is limited research in the area to date.

I’m contacting you to identify the contact information for a case coordinator in your district who would be designated if a child was referred with vision and hearing loss so that I can set-up one, face-to-face interview in a convenient location. This research is completely voluntary and no identifiable information will be included during the data analysis and reporting process. Participants have the right to refuse to answer questions or stop participating at any time.

Do you have any questions I can answer about the study procedures or the rights of participants?

Could you provide the name, phone number and email for a person you believe would fit the description of a case coordinator for referrals for children with vision and hearing loss in your school district?

For your records, my contact information is (614) 602-7998 or herbster@wowway.com if you need to get in touch with me for any reason.

<table>
<thead>
<tr>
<th>If desired person is not available</th>
<th>Hello (Mr./Ms.) XXXXX. My name is Heather Herbster and I am a graduate student from The Ohio State University. I'm calling in follow-up to a letter that was sent to XXXXXX. Is there a better day and time to reach XXXXX? Thank you. I will try back then.</th>
</tr>
</thead>
<tbody>
<tr>
<td>If desired person is hesitant or unwilling following the description and request</td>
<td>Is there another person you believe would be a better contact to discuss the</td>
</tr>
</tbody>
</table>
potential research in the district with?

Can you provide their name and contact information? Thank you for your time.

(At this point I would edit the letter and start the process again)
Appendix D: Follow-Up Telephone Transcript to Case Coordinators
Appendix D: Follow-Up Telephone Transcript to Case Coordinators

Hello, I am Heather Herbster, a graduate student from The Ohio State University. May I please speak with XXXX (case coordinator)?

| When desired person gets on the phone | Hello (Mr./Ms.) XXXX. My name is Heather Herbster and I am a graduate student from The Ohio State University. I received your name from XXXX (administrator). I am completing dissertation research and am in the process of setting up face-to-face interviews with people who have been determined to be case coordinators who work as part of special education evaluation teams to make disability determinations for students who have been referred with vision and hearing loss. Your district was selected from EMIS (Education Management Information System) data reported in the 2012-13 school year as being a district with a child with deafblindness enrolled. Case coordinators can include special education directors and school psychologist. The purpose of the study is to gain a greater understanding of factors that influence the identification process for children who are deafblind from the perspective of professionals from outside of the field of deafblindness (e.g., special education case coordinators-special education directors, school psychologists) because there is limited research in the area to date. This study will not ask for/or reference individual children but is intended to address overall district procedures. This research is completely voluntary and no identifiable information will be included during the data analysis and reporting process. Participants have the |
right to refuse to answer questions or stop participating at any time.

Your name was suggested by XXXX (administrator) as someone to complete a one-time interview as a part of the data collection process. Could you suggest a date, time and location that would be convenient to you?

Do you have any questions I can answer about the study procedures or the rights of participants?

Thank you for your time.

| If desired person is not available | Hello (Mr./Ms.) XXXXX. My name is Heather Herbster and I am a graduate student from The Ohio State University. Is there a better day and time to reach XXXXX? Please feel free to contact me at (614) 602-7998 or herbster@wowway.com in the meantime if you have any questions are need to reschedule. Thank you. I will try back then. |
| If desired person is hesitant or unwilling following the description and request | Is there another person you believe would be a better contact to discuss the potential research in the district with? Can you provide their name and contact information? Thank you for your time. (At this point I would contact the administrator verify the information and send a follow-up email to the person, if deemed appropriate). |
Appendix E: Follow-Up Recruitment Email for Designated Case Coordinators
Appendix E: Follow-Up Recruitment Email for Designated Case Coordinators

Dear XXXXXX,

Thank you for agreeing to participate in the dissertation research study entitled, *Special Education Eligibility and the Category of Deafblindness: Examining the Perspectives of Case Coordinators*, we discussed during our phone conversation on XXXX. This email is intended to confirm the details for our face-to-face interview that will take place as follows:

Date-
Time-
Location-

Attached you will find a consent form that will be provided at our onsite meeting. Please note that participation is voluntary and that you have the right to refuse to answer any questions during the interview process. If you have any questions or concerns before the meeting, please feel free to call me at 614-602-7998 or by email herbster@wowway.com. I look forward to talking with you soon.

Thank you,

Heather Herbster
OSU Ph.D. Candidate
Appendix F: Interview Questions
Appendix F: Interview Questions

1. What is your position within the district, and how does that position relate to your role as a member of the special education evaluation team? Add: Professional background and training?

2. Please describe the initial referral process including who is involved and what role they play?

3. Could you describe the initial evaluation team meeting including who is involved? Is there a primary person who sees the evaluation through in your district?

4. How do you determine the areas of evaluation in an evaluation team report? What background information is important to you?

5. How much influence do you have on the special education evaluation team’s decision-making process?

6. Are there members of the evaluation team that provide information that influences the evaluation team for children with vision and hearing loss?

7. How do you resolve disagreement regarding disability categories?

8. What has been your experience in classifying a child with more than one disability that includes vision and hearing loss?

9. How closely does your special education team look at a student’s history when determining whether he/she qualifies for services?

10. What factors do you consider when determining whether a student should be considered with the label of “deafblindness”? What influences those decisions?

11. What factors may prevent a student from being labeled with “deafblindness”? What influences those decisions?

12. Do you have the resources to evaluate and educate students with deafblindness in your district currently?

13. What is your professional background and training?

14. How many years have you been in the field of education? Other roles?
15. What is your level of comfort in addressing the needs of a child with deafblindness?

16. What factors would keep you from labeling a student with a loss of vision and hearing as having multiple disabilities? Deafblind?

17. How are the following definitions the same? How are the following definitions different?

*Multiple Disabilities*-impairments that occur simultaneously (such as cognitive disability-blindness and cognitive disability-orthopedic impairment), the combination of which causes such severe educational problems that they cannot be accommodated in special education programs solely for one of the impairments. The term does not include deaf-blindness.

*Deaf-Blindness*-Hearing and visual impairments occurring together. The combination causes such severe communication and other developmental and educational problems that the child with deaf-blindness cannot be accommodated in special education programs designed only for children with deafness or only for children with blindness.

18. What level of vision loss is required to be categorized as having visual impairment? Blindness?

19. What level of hearing loss is required to be categorized as having hearing impairment? Deafness?

20. For a child with an initial classification as having deafblindness, what factors could lead to a change in the classification of the child?