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UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

IDENTIFICATION OF YOUNG CHILDREN WITH VISUAL IMPAIRMENTS INCLUDING UNIQUE CHARACTERISTICS AND FACTORS RELATED TO RESPONSIVE SERVICES

A Dissertation Submitted in Partial Fulfillment
of the Requirements for the Degree of
Doctor of Philosophy

DeEtte L. Snyder

College of Education and Behavioral Sciences
School of Special Education
Special Education

May 2018

This Dissertation by: DeEtte L. Snyder

Entitled: *Identification of Young Children with Visual Impairments Including Unique Characteristics and Factors Related to Responsive Services*

has been approved as meeting the requirement for the Degree of Doctor of Philosophy in College of Education and Behavioral Sciences in School of Special Education, Program of Special Education

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ABSTRACT

Snyder, DeEtte L. *Identification of young children with visual impairments including unique characteristics and factors related to responsive services.* Published Doctor of Philosophy dissertation, University of Northern Colorado, 2018

In order to truly meet the unique learning needs of young children with blindness and visual impairment (BVI), it is critical to accurately define the population to create and implement quality and responsive support services. The current analysis utilized existing data gathered from the Babies Count database to examine the defining characteristics of a sample of 588 young children, aged birth to three, with BVI and then used these characteristics to predict the influence of potential barriers to early referral. This study also examined the multiple variables through descriptive statistics and then utilized a multiple regression procedure to determine which variable, or characteristic, contributed to or predicted the age of diagnosis of a vision condition that leads to BVI and the age of referral for specialized visual impairment services within the early intervention (EI) system for children with disabilities aged birth to three.

The study found that the three most prevalent eye conditions were cortical visual impairment (CVI), optic nerve hypoplasia (ONH), and retinopathy of prematurity (ROP). Over 1/3 of the overall sample reported a visual diagnosis of cortical visual impairment. The sample was reported to have a range of visual abilities, with about 35% of the sample either meeting or functioning at the definition of blindness and the remaining with low vision or near normal visual function. In addition to visual abilities, over 80% of the sample were identified as having additional delays, with 1/3 of the sample with severe or profound disabilities. The sample was also found to have large EI support teams with over 40% of the sample reporting more than four EI services and 76% receiving monthly or bi-weekly visits from the specialized visual impairment provider.

Young children with BVI were diagnosed with a visual condition at a mean age of 7.2 months and referred for specialized visual impairment services at a mean age of 9.5 months, with a mean delay of 5.2 months between diagnosis and referral. The variables of primary eye condition (CVI) and etiology (postnatal) were most predictive of later ages for diagnosis of a visual condition. The variables of state (New Mexico) and referral source (medical provider) were most predictive of early referral for specialized visual impairment services.

The descriptive results of this analysis were compared to previous analysis of the Babies Count database by Hatton, Ivy, and Boyer (2013). The top three prevalent eye conditions were the same with CVI as most prevalent in both, but OHN as second and ROP as third in the current study. Both samples had high incidences of additional disabilities. The comparison and the similarities found can assist the field of early education for children with BVI to build a longitudinal perspective of the entire population of all ages of children with BVI.

This study found that young children with BVI have diverse visual and developmental needs. Complexity found within the sample creates challenges in providing appropriate educational services, but also creates opportunities for partnerships and collaboration with other professionals who also provide EI and educational services to this unique population.

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Special thanks go to the 2013 and 2015 International Preschool Seminar Group, now known as the Early Childhood Visual Impairment Alliance for their dedication and commitment to the Babies Count project. The small workgroup created was instrumental

in the improvement of the survey, database, and procedure to collect the vital information about young children with blindness or visual impairments that is critical for appropriate support services. I am blessed to have such wonderful colleagues in the field of education for young children who are blind or visually impaired. Additional special thanks to Dr. Deborah Hatton for her work with previous analyses that we are now able to build upon for the future. Also, to Linda Lyle and Andrea Montano from NMSBVI for their partnership in the whole process.

Last but not least I would like to thank my parents for always believing in me. Even though there were occasions not to, their love and support never waned.

TABLE OF CONTENTS

CHAPTER

LIST OF TABLES

Table

Table

CHAPTER I

INTRODUCTION

Background

In order to truly meet the unique learning needs of young children with blindness and visual impairment (BVI), it is critical to accurately define the population, as well as identify the needs, that are to be supported (Boyle et al., 2011). Surveillance systems are the most cost effective and efficient ways of capturing epidemiologic information about a population as well as the services created to support the needs of a special population (Farel, Meyer, Hicken, & Edmonds, 2003; Ravenscroft et al., 2008). Babies Count is an example of a surveillance system that gathers epidemiologic and demographic information about children aged birth up to 3 years old with BVI, their families, and the early intervention (EI) services created to support them.

Babies Count gathers epidemiologic and demographic information about children and their families including information about their vision and medical diagnosis, presence of additional disabilities, and types of EI support services, specifically visual impairment specialized services. Educational professionals of children with BVI, such as teachers of the students with BVI (TVI), state certified orientation and mobility specialists (O&M), or a developmental specialist employed by a specialized agency providing EI support services for children with BVI, gather information through the completion of a 37-question survey. The survey or data collection form is completed at the child's entry to specialized visual impairment services and then again at exit.

The Babies Count database of gathered information enables researchers to identify the early trends in etiologies of BVI and demographics of children and families. Identification of early trends may forecast a change of the population of all children with BVI in all age groups, as infants and toddlers will enter school systems after they exit early intervention programs at the age of three years old. Forecasting gives a data-driven direction to the field of education for BVI to create, improve, and implement responsive service delivery programs, including personnel preparation programs, to appropriately meet the educational needs of students.

Babies Count started in 1995 to advise the field of education for children with BVI about the characteristics of BVI in children, aged birth to 3, including the leading causes of BVI, and to provide critical data for research to inform EI programs, teacher personnel preparation programs, and the medical community to meet the current and future needs of this diverse population (Hatton, 2001; Hatton, Ivy, & Boyer, 2013; Hatton, Schwietz, Boyer, & Rychwalski, 2007). The Registry of Early Childhood Visual Impairment Consortium Group (RECVICG) was a taskforce formed within the 1995 International Preschool Seminar meeting, which is a collaborative meeting of professionals from specialized service agencies throughout the United States and Canada who provide early childhood educational services for children with BVI. RECVICG developed a surveillance system of collecting demographic data on children with BVI, including their visual and medical diagnosis, family characteristics, and early intervention services they received. This system was modeled originally after a data collection process established by the Blind Babies Foundation, an agency that provides EI support services to children with BVI and their families in central California. The Babies Count project has impacted the fields of EI and education for the BVI by creating a centralized national registry of children that clearly defines the population of young children who are blind or visually impaired where no other exists.

Over the past 23 years of the registry, the project has had many transitions. Appendix A describes the complete timeline of Babies Count to give more details regarding its creation and history. The database was housed the longest, 13 years, at the American Printing House for the Blind (APH) in Louisville, Kentucky, but the project has recently transitioned to the New Mexico School for the Blind and Visually Impaired (NMSBVI). Assisting in the transition was the 2013 International Preschool Seminar participants who created another taskforce, similar to RECVICG, comprised of committed professionals in the field of EI for BVI from the states of Arizona, California, Colorado, New Mexico, Kansas, Kentucky, and Missouri, reflecting a national effort to the continued mission of the project. This taskforce worked together to revise the data collection form and also to develop a new database with an online submission process to bring the project in alignment with today's technology. Appendix B outlines the changes made on the data collection form and gives a comparison of the items on both.

In addition to describing the population and the early trends of characteristics within the population of children with BVI, Babies Count also provides data that can be used to measure the accessibility and responsiveness of EI support services, specifically specialized visual impairment services for children with BVI and their families. Early identification is a critical keystone component of EI (Bruder, 2010; Farel et al., 2003) and reduces potential developmental risk factors associated with vision impairment (Dale & Salt, 2007). The benefits of EI support services are far reaching and the earlier the better; the earlier a child is identified, the earlier a child will benefit developmentally, the family will benefit through support in parenting, and the community will benefit through reduction of later educational costs (Bruder, 2010; Dale & Salt, 2007; Hadders-Algra, 2011; Hatton, McWilliam, & Winton, 2002; Miller et al., 2008).

An important element for quality and responsive EI service delivery is the measurement of early identification (Macy, Marks, & Towie, 2014) and also the accessibility of these services to children and families (Miller et al., 2008). Babies Count accomplishes both by gathering information regarding the age of diagnosis of a visual impairment, typically an eye condition that has a very high risk for BVI, and age of referral to specialized visual impairment services within an EI program. The time between diagnosis and referral can be considered the time the child and family needed to wait for appropriate provision of specialized visual impairment services and may be used as a measurement of responsiveness by EI support service agencies (Miller et al., 2008), which provide specialized visual impairment support.

The National Agenda for the Education of Children and Youth with Visual Impairments, Including those with Additional Disabilities has set the standard for timely delivery of services. Goal #1 states: “Students and their families will be referred to an appropriate education program within 30 days of identification of a suspected visual impairment” (Huebner, Merk-Adam, Stryker, & Wolffe, 2004). However, according to the Babies Count analysis from 2013, it appears that this goal was not met nationally (Hatton et al., 2013). According to Hatton et al. (2103), the average age of diagnosis or identification of a visual impairment is five months of age and the average age at referral to specialized vision services is 10 months. This gap or wait for services of an average of five months does not meet the standard of 30 days created by the National Agenda.

Hatton and colleagues in their 2013 analysis did find differences in ages of diagnosis between the three top eye conditions, Cortical Visual Impairment (CVI), Optic Nerve Hypoplasia (ONH), and Retinopathy of Prematurity (ROP), as well as differences in age of referral (Hatton, et al., 2013). The type of visual condition was the only characteristic addressed in their analysis of the wait time between time of the diagnosis of a visual impairment and the referral for specialized visual impairment services. Other factors, such as geographical location, referral source, or a family characteristic, may impact or contribute to a delay of services and it would be important to explore all the potential barriers to early identification and referral in order to assist programs with improvement regarding timely delivery of service (Miller et al., 2008).

Statement of the Problem

The field of education of children with BVI has historically been focused on children with ocular visual impairments (Solebo & Rahi, 2014); however, there appears to be a dramatic change in the etiologies of BVI towards neurological rather than ocular conditions with concurrent additional disabilities. There is great diversity in children with BVI and therefore great difficulty to generalize across such a population of children with great differences, which includes both visual and developmental differences. Due to this diversity, there is a need to correctly identify the cause of BVI, or visual etiology/medical diagnosis, as the starting point in order to create individualized support (Fazzi, Signorini, Bora, Ondei, & Bianchi, 2005). For instance, knowledge of etiology of the VI (such as ocular versus neurological), level of visual function, and presence of additional disabilities will differentiate the intervention strategies (Chen, 2014; Fazzi et al., 2005; Ferrell, 2011). The field of education for children with BVI needs to constantly update the characterization and description of the population in order to meet the changing needs of children with increasingly diverse educational and support needs.

According to the analysis of data available from Babies Count in 2013 that includes 5,931 babies (children aged birth to 36 months of age) from 28 states in a six-year period of time, the most prevalent eye condition that leads to uncorrectable visual impairment is CVI, a neurological vision condition, which comprised 25% of the sample (Hatton et al., 2013). The data indicated the second and third cause of BVI as the ocular conditions of ONH and ROP, both with 11% of the overall sample of children with BVI. The presence of additional disabilities occurred in 65% of the entire sample, and is highest amongst children with CVI, as 85% of children with CVI had additional disabilities, 66% of children with ROP had concurrent additional disabilities, and 50% of children with ONH had concurrent additional disabilities (Hatton et al., 2013).

These results indicated a remarkable incidence of additional disabilities and may portray the diversity of children with BVI, given that additional disabilities were a very broad categorization. The changing and diverse description of this population challenges service delivery programs to meet the unique needs of a young child with BVI and additional disabilities. It also challenges personnel preparation programs to implement a curriculum that adequately prepares teachers of students of all ages with BVI, including those with diverse additional disabilities, to meet the individual needs of all students.

The overall goal of EI support services for children with BVI is to preserve and optimize vision (Fazzi et al., 2005; Ferrell, 2011), to improve cognition through multi-sensory experiences (Chen, 2014; Fazzi et al., 2005; Ferrell, 2011), and increase independence and adaptive skills (Fazzi et al., 2005; Ferrell, 2011; Pogrund & Fazzi, 2002). Often a visual impairment leads to issues in social emotional arenas, including to parental depression including an interference of attachment and two-way communicative developmental delays (Hatton et al., 2002). Therefore, families of children with BVI need immediate information regarding visual diagnosis and their child's unique learning style (Ferrell, 2011; Pogrund & Fazzi, 2002), especially those with additional disabilities.

Also, it is imperative that the field of EI for BVI measures the ability to provide services as early as possible. The National Agenda has set the standard of referral to be within 30 days of a child's identification of a suspected visual condition with high probability of causing a developmental delay (Huebner et al., 2004). Therefore, the field requires a way to measure this standard and the responsiveness of specialized visual impairment services to young children who are identified with BVI. Barriers, or potential barriers, to specialized vision support services should be evaluated to identify them so solutions can be implemented to assure all children with BVI are receiving responsive and appropriate support services.

Rationale for the Study

Since the field of EI for the BVI has a national registry and surveillance system called Babies Count, which helps to define the characteristics of the population of young children with BVI, this study utilized the information to assist the field with program development to create and implement appropriate, effective, and responsive EI supports for children with BVI and their families. This research study examined the diversity within the population of children with BVI through a careful and detailed look at the various characteristics of individual children. The data gathered was added to existing data for longitudinal analysis that would enable generalization and greater understanding of the entire population of children of all ages with BVI (Hatton, 2001).

Knowledge of the existence of diversity within the population of young children with BVI should be used in the training of professionals who provide EI support services for these children and their families. Effective interventions are those that match and meet an individual family's needs and wants (Luckner & Velaski, 2004; Schwartz, 2002). Parents of children with BVI are requesting professionals who understand their child's BVI and unique learning needs. A study by Speedwell, Stanton, and Nischal in 2003 found parents of children want to be told about their child's BVI sooner rather than later. Also, they want to know about appropriate and beneficial educational resources, specific to their child's visual condition (Speedwell et al., 2003). The results of the analysis aided the ability of medical and educational professionals to form partnerships to address timely service delivery, especially for information regarding BVI.

Since previous analysis of Babies Count data only addressed descriptive analysis of variables (Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007), the current study looked at variables to explain more specifically the time gap that exists between the age of diagnosis and age of referral to assist with responsiveness of child find procedures for children with BVI. In all three previous analyses and publications a deeper analysis was suggested for further research, as Hatton and her colleagues believed more detailed breakdown of the data would potentially lead to greater understanding of the barriers to early identification of BVI, as well as the accessibility to appropriate resources. These recommendations also included the accessibility to specialized visual impairment services at a young age by an examination of the diverse variables related to the referral to EI support services, such as types of BVI, referral sources, family characteristics, and geographical locales (Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007). More extensive exploration of variables that contribute to the lack of accessibility to specialized visual impairment services will allow the field to improve the quality of service accessibility, responsiveness, and provision. EI support service programs across the country may assist each other in program evaluation and program improvement regarding the responsiveness of their service delivery (Macy et al., 2014) for children with BVI and their families, including programs designed to train specific visual impairment service providers. This information is especially important to assure that families of children who may have BVI are being offered the EI services/supports that best meet their needs (Hatton et al., 2002; Luckner & Velaski, 2004; Schwartz, 2002)

Finally, when data are known to define the characteristics, including trends and service needs, within a population, the data can be used to describe the need and rationale for funding (American Foundation for the Blind Public Policy center, n.d.; Boyle et al., 2011). In order to develop appropriate programs, both for direct and indirect service delivery for children with BVI including university programs designed to train teachers, funding is critical. Establishing a definition of the actual population of children with BVI is an essential component of the rationale for funding to specialized BVI support programs to provide for educational and medical needs of these children. A clear description of the population of young children with BVI will assist with rationale for funding requests of local, state, and national programs.

Theoretical and Conceptual Framework

This research study was based on two critical components of EI within the general theoretical construct of constructionism, as all knowledge is built on existing knowledge (Crotty, 1998). First, in order to create and implement EI service delivery programs to support young children with BVI and their families, it was important to understand the basic composition, including both its diversity and homogeneity (Boyle et al., 2011). If knowledge does not exist regarding the defining features of this special population, the needs will not be identified and therefore not met. Needs of the field includes training professionals to work with young children and their families, establishing best practices, and justifying funding sources for maintenance of appropriate EI support service programs.

The second component was the concept of earliest is best in EI support service provision (Bruder, 2010; Dale & Salt, 2007; Hadders-Algra, 2011; Hatton et al., 2002). If knowledge does not exist regarding how, or when, children are identified and referred to specialized visual impairment services, then the various support programs within the early intervention system cannot improve their responsiveness to children with BVI and their families, who are requesting these services.

Purpose of the Study

The first purpose of this study was to provide the field of early intervention for the visually impaired with information regarding the current trends such as leading eye conditions causing BVI, both ocular and neurological, and a description of the characteristics of children's medical and educational complexities beyond their visual conditions. An analysis of the first year of the Babies Count data, after its transition and revision, accomplished this first purpose. The results provided the field of EI for BVI with additional longitudinal data to describe the diverse nature of the population of young children with visual impairments, as well as a potential longitudinal forecast of the entire population of all children with BVI.

The second purpose was to measure the responsiveness of services, to assess the field's ability to meet the standard set by The National Agenda regarding early referral and to provide information regarding the variables related to the time span between age of diagnosis and age of referral. This study has given a data driven direction to states, local communities, and service delivery agencies as they create, improve and implement programs of EI services for children with BVI and their families, including university teacher training programs.

Research Questions

The analysis replicated the research questions from earlier analyses of Babies Count including descriptive analysis of the most prevalent eye conditions, presence of additional disabilities, and the time gap between age of diagnosis of an eye condition that led to BVI and the age of referral to specialized visual impairment services in EI. Additionally, specific data analysis was completed to examine more closely the time gap between age of diagnosis and referral and the variables that might be contributing to it.

Q1 In the last year, what are the most prevalent child, family, and service characteristics of infants and toddlers with blindness and visual impairment, including

  a. What is the gap between age of diagnosis of visual impairment and age of referral to specialized vision services?

Q2 What is the relationship among child characteristics, family characteristics, and service characteristics and
  a. age of diagnosis of blindness or visual impairment; and
  b. age of referral to specialized vision services?

Q3 Which variables predict the age of diagnosis of blindness or visual impairment and age of referral to specialized vision services?

Q4 How do the results from this study compare to the results reported in the 2013 Babies Count analysis (Hatton et al., 2013), including
  a. Trends in child and service characteristics; and
  b. Differences that may be relevant for EI service providers?

Limitations

This study utilized and analyzed data existing within the Babies Count database. The use of secondary data limited the study to the data that was available. While Babies Count is a nationally available survey, not all states or EI support programs participated in data collection. A limitation was found related to the inability to obtain a true response rate among all EI support programs that provide supports for children with BVI and their families and led to an incomplete representation of all children with BVI. A potential sample bias existed, within the convenience sample, as the respondents were from highly motivated agencies committed to the Babies Count registry and its data collection process.

Due to this first limitation of convenience sampling, the sample did not include all children with BVI. Elimination of children in the sample was due to three conditions: (a) the individual child may not have been identified as a child with BVI; (b) the child was not currently receiving specialized visual impairment services through their EI support program; or (c) the child was receiving specialized vision services but not through an agency participating in the Babies Count data collection process. There was a limitation of not capturing all the information on all children, which reduced the ability to generalize to the general population of children with BVI, especially since the sample was not randomly assigned.

Another limitation related to the utilization of a secondary database, was related to internal consistency. Babies Count is a national database with many different agencies and professionals providing information. Therefore, the training in the participation of the registry and completion of the survey was varied and potentially led to a diverse ability to complete the data collection process with fidelity. The existence of possible inconsistency with data collection may have led to issues related to the reliability of the data.

CHAPTER II

REVIEW OF LITERATURE

This literature review examined the limited knowledge base on the prevalence and characteristics of young children with blindness and visual impairments (BVI) in the United States. This review was both diverse and complex based on the assumption that all children with BVI are different. This assumption was based on the individual nature of each child's visual etiology, environments where they reside, and the variation in supports available within the vast medical and educational systems across the country. This review explored these issues through both an educational and medical research lens to highlight the need for a systematic and nationwide investigative method of gathering this critical information regarding the characteristics and needs of young children with BVI. This information will advise service program developers and implementers, including teacher preparation programs, to create the required supports for children with BVI and their families that are appropriate and responsive.

Incidence and prevalence are similar yet different constructs. Incidence is a measurement of rate of occurrences of new cases (Muller, 2011; Shields & Twycross, 2003). In order to understand if new cases of BVI are being reported, the knowledge of existing BVI is needed. Prevalence is thought of as the proportion of all cases, new and existing, within a given population at a given time. (Muller, 2011; Shields & Twycross, 2003). Prevalence is measured through a variety of surveillance systems both nationally and internationally, including surveys from the Centers for Disease Control (CDC) such as the National Health Interview Survey (NHIS) and the National Health and Nutrition Examination Survey (HNANES). Crews et al. (2012) defined “A true surveillance system is an active, dynamic process that feeds data to end users who can effect change in policy and programs” (p. 52). Population surveys take an in-depth look at a specific group of people, usually based on a geographic area or other category such as in a school or within a disability grouping. This method is the preferred and most accurate way to obtain prevalence data, but such procedures are sometimes both logistically difficult and costly (Steinkuller et al., 1999).

Information regarding the prevalence of any medical condition, such as BVI, which has a great risk of a developmental delay or disability in young children, is important information to gather for many reasons. First, prevalence information helps to define a particular population and the specific educational, medical and social support needs of the specifically defined population. In addition to defining a population based on a common characteristic such as a visual disability, prevalence information allows for trends of the characteristics, including changes or variations, to be monitored within the population (Boyle et al., 2011; Crews et al., 2012; Kirchner, 1999a; Kirchner & Diament, 1999; Yeargin-Allsopp, Murphy, Oakley, Sikes, & The Metropolitan Atlanta Developmental Disabilities Study Staff, 1992).

Second, prevalence information is useful when evaluating the effectiveness of prevention strategies in the medical community to avoid the issue all together, but also educational services to intervene potential disability factors (Boyle et al., 2011; Yeargin-Allsopp et al., 1992). This may be especially important in the community or field for education of the BVI given the possible trends of a changing population and the need for policies to also change or adjust to the perceived need. However, Kirchner (1999b) cautions that prevalence does not equate to need for service or demand for service and may “deflect attention from the gap between the number of people who could benefit and the number who actually receive” (p. 53). This important point illustrates the need to not only count the number of children with BVI, but also to identify the individual characteristics of each child and the large diversity and heterogeneous nature within the population of children with BVI. Kirchner and Schmeidler (1999) also caution that when the number of children with BVI are combined, which is a necessary and common statistical practice due to the low incidence of BVI, the diversity of the various characteristics and difference between individual children are inadvertently hidden or unseen (Kirchner & Schmeidler, 1999).

In addition to differences in how the population of children with BVI is defined, it is important to conceptualize vision loss as a vastly multifaceted condition. Vision loss includes many variables related to biologic, economic, and sociologic conditions (Lee et al., 2012) that varies throughout the world, but also sometimes within local communities. So, while many of the surveillance systems vary in their measurement strategies and procedures, they all strive to obtain information holistically through a public health lens to then plan, implement, and continuously evaluate both health and educational practices to better the lives of people.

Finally, when data defines the characteristics, including trends of medical conditions and developmental needs within a population, this information can be used to describe the support service need and rationale for funding (American Foundation for the

Blind Public Policy center, n.d.; Boyle et al., 2011). In order to develop appropriate programs, both for direct and indirect service delivery for children with BVI including university programs designed to train teachers, funding is critical. Establishing a description of the actual population of children with BVI is an essential component of the rationale for funding to support programs to provide for educational and medical needs of these children.

Scope of Review

The journal articles and additional literature from conference presentations (deVerdier, 2016; Ravenscroft, 2016) included in this review focus on a variety of studies examining the surveillance systems currently in practice to measure the prevalence rates of children and adults with BVI, in the United States and around the world. This information was focused on both medically and educationally based surveillance systems, since BVI involve medical conditions, such as a specific eye condition or disease that causes developmental disabilities potentially necessitating educational interventions. The review included a broad field of studies including the review of worldwide prevalence data, primarily focused on adults (Crews et al., 2012; Gilbert, Anderton, Dandona, & Foster, 1999; Hendershot & Crews, 2006; Hendershot, Placek, & Goodman, 2006; Kirchner, 1999a; Kirchner & Diament, 1999; Kirchner & Schmeidler, 1999; Kong, Fry, Al-Samarraie, Gilbert, & Steinkuller, 2012; Solebo & Rahi, 2014; Steinkuller et al., 1999), and community based, specific population studies of children with concurrent incidence of visual impairments and developmental disabilities (Boyle et al., 2011; deVerdier, 2016; McClelland et al., 2007; Flanagan, Jackson, & Hill, 2003; Haddad et al., 2005; Nielsen, Skov, & Jensen, 2007; Ravenscroft, 2016; Ravenscroft et al., 2008;

Yeargin-Allsopp et al., 1992). Also, articles with prevalence information regarding etiologies of BVI in specific areas or populations in the United States (Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007; Lewerenz, Peter, & Ford, 2016; Wall & Corn, 2004) were included.

Furthermore, this literature review included a brief exploration of child find procedures in early intervention services, which includes identification of qualifying conditions and the referral process (Farel et al., 2003; Macy et al., 2014; Miller et al., 2008; Mott & Dunst, 2006; Speedwell et al., 2003). Also included was a brief examination of ethnic, racial, and economic disparities within the medical and educational systems (Lee et al., 2012; Kirchner & Schmeidler, 1999; Zhang et al., 2012), which may assist the field of early childhood education for BVI with information regarding the accessibility and responsiveness of support services.

Findings in the Literature

When looking at the variety of surveillance systems used to measure the prevalence of BVI it was necessary to examine the methods used to define the human condition of BVI. Hendershot et al. (2006) explained that there are two ways to view visual impairment. One way is with a medical model that defines BVI objectively as a direct result of a physical condition, such as a specific visual condition or disease, and also a clinical measurement of the impact, such as visual acuity. The second way is through a subjective and social model that defines visual impairment through the personal perception of the limitation and a personal view of the interaction with the environment. Personal perception of BVI is a much more subjective measurement since it is based on an individual person’s self-reported interpretation of their experiences (Hendershot et al., 2006).

The National Health and Nutrition Examination Survey (NHANES) used clinical assessments for definition of eye information (Crews et al., 2012) in addition to self-report questions regarding activity and participation. In 1999 and 2004, 18.2% of the population over 45 years old reported moderate or extreme difficulty with activities that required sight and the clinical assessments indicated BVI was present in only 6.4% of the population (Hendershot et al., 2006).

Another survey to gather information on BVI in adults was the Survey of Income and Program Participation (SIPP), which is part of the U. S. Census Bureau survey and includes two self-report questions regarding vision. In 1996, SIPP indicated 28.4 per 1000 adults reported had difficulty seeing words and letters in ordinary newspaper print, even wearing corrective lenses, in comparison to 8.5 per 1000 were unable to see words or letters in ordinary newsprint (Hendershot et al., 2006). It was unknown regarding the guidance people were given on the difference between the difficulty to see words and the inability to see words. This incongruity may indicate that self-reported, activity participation type questions are a potentially unreliable method of reporting actual visual impairment due to variation in each person’s interpretation of the question.

The Lighthouse Survey was another self-report survey for adults over 45 years old and used a more general view of BVI than SIPP. In 1994, 17% of adults self-reported a vision related disability that increased with age: 14.4% for people 45 to 54 years old and 26.5% for those aged 75 years or older (Hendershot et al., 2006). Again, the definition of visual related disability was not known and may also have had many interpretations based on individual experiences.

The explanation of the discrepancy between the prevalence rates was the lack of consistency regarding the questions used to define BVI (Crews et al., 2012). To assist with the development of a clear conceptual understanding of visual impairment, the International Classification of Functioning, Disability and Health (ICF), part of the World Health Organization (WHO), was created to provide a way to conceptualize a disability where function and impairment is a complex interaction between health related condition and perceptual factors of the environment and personal characteristics. ICF is not an actual measurement, but a system of classification (Hendershot & Crews, 2006). Categories of questions include body functions (i.e. acuity), body structures (i.e., etiology), activities and participation within nine individual categories, and environmental factors used as levels to classify severity and/or abilities. This classification system was comprehensive and yet a versatile tool for many purposes with validity (Hendershot et al., 2006). IFC "creates a conceptual taxonomy for portraying human experiences that is useful for disability research because it illustrates the dimensional characteristics of the lived experiences of disability" (Crews et al., 2012, p. S33).

NHIS was considered the best source of ICF compatible prevalence estimates and aligns with ICF classifications when BVI related questions were added to the survey in 2002 (Hendershot et al., 2006). Prior to 2002 and since 1996, the family and sample child core questionnaire included no direct questions regarding BVI; however, two questions regarding BVI were included in the adult section. Then in 2002, a vision supplement of seven additional questions was added. Estimates from the vision supplement of the NHIS indicated 23% of the US population had a vision related disability based on the criteria of either having an impairment in at least one body structure, had a perception of being limited in an activity, or used a preferred environmental modification (Hendershot et al., 2006). Hendershot et al. (2006) reported that NHIS, specifically the vision disability supplemental survey, aligned well with ICF classifications and provided a "substantial range of data on vision-related disability" (p. 815). However NHIS was primarily for adults over the age of 18 only and not for children.

The disparity between the reported prevalence of BVI of these surveillance systems (NHANES, SIPP, Lighthouse, and NHIS) was striking, yet may be expected given the combination or comparison of data due to many factors. One main factor was the method of harmonization, or rather the coordination or combination of existing data. According to Hendershot and Crews (2006), there were two ways to harmonize data. The first method was pre-harmonization. This method attempted to design studies to collect and report in the same way, prior to data being collected, as well as used the data for the same purpose. The second was a post-harmonization with post hoc manipulation of the data and completed after data is collected (Hendershot & Crews, 2006).

An example of a combination of post- and pre-harmonization was the World Health Surveys (WHS) by WHO using ICF classification codes. WHO attempted a post-harmonization process to allow the data, with different measurement criteria, to be more comparable resulting in more useful information. The result was Disability Tabulations (DISTAB), which was a supplement of ICF and evaluated the estimates of BVI within

ICF. Within DISTAB, each participating country had a different surveillance system and individual surveys with different questions related to visual disability. All the surveys focused only on adults 18 year or older and only one similarity existed in the results amongst six countries (Australia, Canada, France, Netherlands, South Africa, and the United States): Visual disabilities increased in age. While this information was helpful according to Hendershot and Crews (2006), the post harmonization process was "crude at best" (p. 21). The central issue included whether the disparities reflected a real difference or similarity in the population or the disparities were caused by the methods used in each different survey (Hendershot & Crews, 2006). There was no way to know because of the varied methods of each study and the inability to perform an accurate or valid comparison did not allow the data to uncover other assumptions.

Crews and his colleagues in 2012 demonstrated this difficulty in their study that focused on an evaluation method to compare the conceptual clarity of the various forms of measurement of visual differences between 12 surveys worldwide. Using WHO's ICF classification system for association, the 12 surveys had 100 different questions regarding the measurement of visual impairment with no consistent measures of BVI. The large variation in types of questions, mostly self-reported, led to the large variation in estimates (Crews et al., 2012; Zhang et al., 2012).

NHANES was the only surveillance system to use clinical visual acuity measurements yet was still not consistent in reporting. This lack of consistency greatly limited the ability to characterize or define the population due to the lack of consistent data including lack of conceptual clarity of BVI. Overall this was a problem for both the medical and educational fields because the ability to "Assess the prevalence and distribution of visual impairment is critical to developing effective public health policy, yet there is no systematic vision health surveillance system in US." (Crews et al., 2012, p. S31).

Zhang and colleagues in 2012 used both NHANES and NHIS to look at the racial/ethnic, educational, and economic differences in the population of adults who were BVI. They reported on three racial/ethnic groupings (white, black, and Hispanic). The highest rate of diabetic retinopathy occurred in the black group, and there was no difference between white and Hispanic groups. However, there was an increase of cataracts and age related macular degeneration within the white group. Another notable finding indicated a high rate of diabetic retinopathy in low education and low-income classifications of all racial/ethnic groups. They indicated this finding might be due to access or utilization of eye care, as the low education and economic group may be the least likely to receive or seek out eye health care (Zhang et al., 2012).

Kirchner & Schmeidler (1999) warned that while statistics on race, ethnicity, income, and education were widely collected and available, the data regarding visual impairment is rare, inconsistent, and not standardized. Often researchers combined visual impairment data for the purpose of statistical analysis and this practice may have essentially obscured the real difference meant to be uncovered. When unstandardized data were combined using an imperfect post-harmonization process (Hendershot & Crews, 2006), it may not have accurately identified the real racial, ethnic, income, and educational inequities within the BVI community (Kirchner & Schmeidler, 1999).

Surveillance on Childhood Blindness Around the World

According to Solebo and Rahi (2014), “visual impairment in childhood is uncommon but the population of children with VI is complex and heterogeneous”, (p. 375). Visual impairment and blindness in children fell within two basic groups. The first was BVI due to an ocular condition and often was the only impairment of the child. The second, however, was BVI due to neurological issues and sometimes was associated with another developmental disability. Frequently there was also a combination of both ocular and neurological BVI and may or may not have included additional disabilities. Each group, as well as each child, differed significantly and individually in terms of health, educational, and social needs (Solebo & Rahi, 2014). Understanding the needs of children, and groups of children, was as complex and diverse as the individuals themselves.

Gathering information consistently regarding the prevalence of childhood BVI was difficult (Solebo & Rahi, 2014). Some of the limitations for prevalence studies on children included the ability to access data. First, the ability to accurately measure BVI in children young children under the age of four was not always possible due to language and cognitive abilities. Often there was a need to repeat measures for reliability, but this was not always logistically possible. Also different methods and/or individual evaluator skills needed for identification of individual acuity measures, such as forced preferential looking tests, affected the validity of the process and were not reported in most studies.

The second issue was sample size. Many studies used a specifically defined sample, such as a convenience sample, like rural or special education populations, which were easier to identify and describe. Schools for the blind often served as accessible and affordable sources, however they still did not account for all children with BVI for a comprehensive representation needed for generalization (Steinkuller et al., 1999).

Third and related to the second, was the issue of incomplete ascertainment of cases. Researchers may have reached all in a particular school, but not all children within the larger community for a variety of reasons. Also, though some countries have national registries, such as Canada, the United Kingdom, Finland, Kuwait, and Australia, there was no standardized worldwide data collection procedure, so the data were not always comparable (Kong et al., 2012; Solebo & Rahi, 2014) or able to be harmonized (Hendershot & Crews, 2006). Also, even though these counties had a compulsory registry, they may not be all-inclusive, such as in Ireland as only 37 % of children were registered (Solebo & Rahi, 2014) though the registry was mandated. These validity and reliability issues appeared to be a persistent issue in prevalence studies in general.

In 2010, WHO had four categories for the definition of visual impairment, including normal vision, moderate visual impairment, severe visual impairment, and blindness (Kong et al., 2012). Moderate and severe visual impairment together was referred to as low vision. According to Kong et al., (2012), WHO determined in 2010 there were a total of 285 million people in the world considered to be visually impaired, with 39 million blind and 246 million considered low vision. Children comprised 1.4 million of the total, and 75% of the entire sample lived in developing counties (Kong et al., 2012). Additionally, the WHO categorization was used widely but not universally accepted, so comparability was difficult (Solebo & Rahi, 2014).

Economy played a major role in rates and types of childhood blindness around the world. This was demonstrated by the 1992 WHO prevalence information of wealthier nations. In the United States, Canada, Japan, and Western Europe, the estimated prevalence of BVI was approximately 0.3 per 1000 or within a range of .10 to .41 (Steinkuller et al., 1999). In England, Wales and Scandinavia, which have compulsory blind registries, prevalence increased with age, possibility because of the ability to accurately assess older children than younger and also the presence of acquired or progressive disorders. For children younger than four years, the prevalence was .1 per 1000, then jumped to .33 per 1000 for children aged 0-10 years (Gilbert et al., 1999). In Scandinavia where the registry was also compulsory, the prevalence was 0.15 per 1000 and in Iceland it was .36 per 1000 for ages 0-14 years. Gilbert et al. (1999) suggest the data indicated a 10-fold difference in prevalence between wealthy and poor counties with 0.1/1000 in wealthy and 1.1/1000 in poor. In Asia it was 0.9 per 1000 (Steinkuller et al., 1999); in Nepal specifically the rate was .61 to .65 per 1000 and in China the rate was .94 per 1000 for 0-13 years (Gilbert et al., 1999). In Africa, the prevalence rate was 1.1 per 1000 (Steinkuller et al., 1999).

In addition to increased numbers of children with BVI in poorer counties, there also was a difference in the types of visual conditions that lead to BVI (Kong et al., 2012). The leading cause of blindness in developing or very poor counties was an infectious disease in the eyes, which in developed or more economically rich counties was not an issue. Also, retinopathy of prematurity (ROP) was increasing in middle-income counties due to medical advances with premature babies, compared to higher income countries where ROP was decreasing, also due to medical advances, but non-existent in developing counties (Gilbert et al., 2005). Though ROP was decreasing in higher income counties, children born prematurely may have had an increase of neurological conditions and potential cortical visual impairment (CVI), especially in the smaller babies born very early (Gilbert et al., 2005; Kong et al., 2012).

In a recent study in Scotland, a geographical measurement of deprivation and cortical visual impairment (CVI) was correlated (Ravenscroft, 2016). The Scottish Index of Multiple Deprivation (SIMD) measured social deprivation in specific geographical areas in Scotland, and the sample included children aged birth to 16 with CVI from the years 2003 to 2014, which accounted for 192 children and determined CVI to be the leading cause of BVI in Scotland. Overall results found a strong correlation of the prevalence of CVI to areas with high social deprivation (r=-0.84), but not a correlation between all conditions of BVI (r=-0.48) or BVI conditions excluding CVI (r=-0.28) and social deprivation. This correlation indicated the less well off a specific geographic area was, even in a higher income country, the more likely the prevalence of CVI was higher than more economically advantaged areas (Ravenscroft, 2016).

Building the knowledge base about the prevalence of BVI in the United Kingdom, the following studies focused on types of conditions resulting in BVI and the presence of additional disability in children living in England, Scotland, and Ireland. A population based incidence study in England called the British Childhood Visual Impairment Study (BCVIS) was conducted in 2000 (Solebo & Rahi, 2014). The investigation did not look at overall prevalence, but focused on the occurrences of types of visual conditions, which may have caused BVI in newly diagnosed cases within a given year. Of 493 newly diagnosed children with BVI, 50% were diagnosed with CVI, 28% were diagnosed with optic nerve hypoplasia (ONH), and 29% were diagnosed with a broad range of retinal conditions, not just ROP. Also, 77% of the 493 children, with a range of BVI conditions, had concurrent additional disabilities (Solebo & Rahi, 2014). In addition to prevalence of visual conditions, Solebo and Rahi (2014) suggested that there was an increased risk of severe visual impairment or blindness in ethnic minorities, low-income families, and low birth weight babies due to neurological damage to white matter or the optic nerves. These results from one county supported the global results from Kong et al. (2012).

The Visual Impairment Scotland (VIS) notification project in Scotland, which is a registry or notification system of children who are visually impaired, identified 850 children with 75 different eye conditions during a five-year period of time between March 2001 and March 2006 (Ravenscroft et al., 2008). The leading eye condition was cortical/cerebral visual impairment (CVI), with a percentage of 21% in the sample. However two neurological conditions, hydrocephalus and peri-ventricular leukomalcia (PVL), were both at 3% of the sample and were also considered in the top 14. These two neurological conditions are not actual visual conditions, but rather contribute to, or can cause, the visual condition of CVI, so statistically could be added to the CVI category. The second vision condition in prevalence was albinism with 8% of the sample, indicating a 13% or more difference between the first condition, CVI, and the second, albinism. Also, half of the sample (51%) had BVI due to conditions of the brain or neurologically based BVI, and 71% of the sample had additional disabilities which include learning difficulties, cerebral palsy and global development delay. Regarding the time of etiology, 62% were prenatal, meaning the visual condition to lead to a visual impairment occurred before the child was born, 20% occurred during the peri-natal period (or directly after birth), and 5% occurred post-natal, or sometime during childhood. (Ravenscroft et al., 2008).

Flanagan et al. (2003) examined the prevalence of BVI in another United Kingdom country, specifically the South and East Belfast areas of Ireland. Their study focused on children aged birth to 19 years old. They used the WHO definition of BVI and utilized visual acuity tools, but also functional behaviors to measure the level of BVI for each child. They discovered a prevalence rate of 1.61 per 1000 as BVI. Even though Ireland has an official registry, children with CVI might not be included in the registry due to the difficulty or inability to identify BVI, so the results may have been an under-estimate of the actual prevalence. Their study also included those with concurrent disabilities, and their sample found 32% of the children with normal development, 25% of the children with mild/mod disabilities, and the remaining 43% of the children experienced global or severe disabilities. Of all the visual conditions examined, CVI was present in 45% of their sample, and CVI combined with optic atrophy (OA) was the most common co-existing vision conditions. They did report a number of limitations in their study. Those limitations included complications regarding the logistics of a complex assessment for etiology. The limitations included the inability to (a) obtain the accurate age of onset, (b) identify the primary eye condition due to multiple co-existing conditions, and (c) measure the functional impact of BVI. Also they experienced methodological challenges because children aged birth to two years old are often difficult to assess, resulting in differing terminology amongst professional groups reporting information. Also visual acuity was difficult to quantify in children with neurological visual impairment such as CVI. Regardless, their findings indicated a changing trend in BVI in children, which include isolated ocular conditions leading to BVI decreasing, ocular and neurological conditions co-existing more frequently, and finally, the presence of additional disabilities increasing (Flanagan et al., 2003).

Another study in Ireland was conducted by McClelland et al. (2007), and specifically looked at the school for the blind located in Northern Ireland. The study was a longitudinal retrospective study that examined the primary visual conditions, visual acuity, and presence of additional disabilities of 8th year students from 1975 to 2004. The study found similar results to the Flanagan et al. (2003) study, including a large percentage of students with additional disabilities, representing 38.7% of the sample, and an increase of cortical visual impairment of 4.5% of the sample in 2004 when compared to 2.1% in 1975. The leading cause of BVI was albinism in the overall sample at 20.3%. Though the enrollment of the school also decreased through the years, the authors believed the numbers reflected a decrease due to many students with BVI participating in mainstream educational placements in their local communities rather than a residential school for the blind. Also the prevalence of specific visual conditions was reflected as changing with correctable ocular conditions, such as cataracts and glaucoma decreased, and non-correctable conditions, such as albinism or CVI, increased (McClelland et al., 2007).

In other areas of the world with similar economic standing as the United Kingdom, prevalence studies have also found a large percentage of children with BVI due to neurological visual impairment conditions, such as CVI, and also concurrent additional disabilities. A study conducted in Brazil by Haddad et al. (2005) specifically looked at the prevalence of BVI in children with existing developmental delays. According to the Brazilian Geography and Statistic Institute, the prevalence of BVI was

0.6 per 1000 in Brazil. Haddad et al. (2005) examined a sample of 3129 children with a range of developmental disabilities, including BVI, between the ages of 2 months to 15 years, with a mean age of 5 years, from March 1998 and March 2005 at the Ophthalmic Low Vision Clinic of Laramara in Brazil. They found 1567 children, 50.1% of the sample, were BVI only, but 1562 children, 49.9% of the sample, had disabilities in addition to BVI. Of the group with additional disabilities, over 50% were profoundly visually impaired or blind. The cause of BVI was diverse yet included 37% optic atrophy and 22% CVI. In the CVI category, 46% was due to hypoxia ischemia (brain damage due to lack of oxygen), but almost 20% was due to infection of the brain, such as meningitis or macular retinochoroiditis due to toxoplasmosis. CVI was the third cause of BVI overall. These key findings may lead to a better understanding of the causes of BVI in populations with developmental disabilities, especially those due to infectious diseases and could possibly lead to prevention (Haddad et al., 2005).

Nielsen et al., (2007) conducted a comparable study in Denmark and also examined a sample of children with a variety of developmental delays, including BVI. Their study encompassed 97% of all children with developmental delay in Denmark, which was a total 1,126 children, and found that 10.5% had some level of BVI. This number represents not all the children in Denmark with BVI, but rather the number of children who have developmental delays or disabilities and BVI concurrently. Regarding severity of vision of the entire sample of children with BVI, 87% were low vision or visually impaired, 10.5% were severely visually impaired or blind, and 2.5% were unable to be measured for acuity. Also many of the children were also found to have very low IQ scores. Thirty-seven percent had a less than 50 IQ, indicating that more than 1/3 of the children with concurrent developmental delay and BVI were significantly impacted developmentally (Nielsen et al., 2007).

In Sweden, a 20 year retrospective study from 1988 to 2008, examined the etiology in children who were either totally blind or had light perception only (deVerdier, 2016). The study involved an extensive file review of medical and educational records for children with identified BVI in the entire country. The study located 150 children within the study criteria and found approximately seven children within each year of the duration of the study. These children were categorized not only within individual visual conditions, but also the medical location and the time of the onset of the visual condition. Locations were defined as ante-chiasm, or in front of the optic chiasm, indicating primarily an ocular abnormality, and retro-chiasm, or behind the optic chiasm, indicating a primarily neurological abnormality. The time of onset were defined as either prenatal (before birth) or peri/postnatal (after birth). Out of 150 children in the sample, 135 children had visual conditions that were located ante-chiasm, or ocular in location, and only twelve out of 150 were retro-chiasm, or neurological in location. The three most prevalent prenatal/ante-chiasm diagnoses were identified as optic nerve hypoplasia (ONH), Leber's congenital amaurosis (LCA), and optic atrophy. Retinopathy of prematurity (ROP) was the primary diagnosis associated within the peri/postnatal ante-chiasm disorders grouping. Regarding the retro-chiasm, ten of twelve were various cerebral malformations, considered prenatal, and only 2 were due to trauma that occurred peri/postnatal. These statistics indicated 90% of children who are totally blind or have light perception have an ocular eye condition only that developed before or at birth (deVerdier, 2016).

Additionally, deVerdier (2016) examined the prevalence of Autism Spectrum Disorder (ASD) concurrent with BVI and found ASD as extremely high incidence in this population of children who were totally blind or had light perception vision only. Approximately 2/3 of the sample either met the criteria for ASD, 31%, or had some identified autistic tendencies, 38% (deVerdier, 2016). However, the study did not describe the difference between autistic tendencies and repetitive behaviors many children with limited or no vision sometimes exhibit, often referred to as “blindisms”. Amongst the children with concurrent conditions of BVI and ASD, the leading visual etiologies were ROP (37%), ONH (28%) and LCA (14%). The study also reported the incidence of ASD within each of these eye conditions. The findings showed that 70% of the children with ONH also had ASD, 58% of children with ROP also had ASD, and 35% of children with LCA also had ASD (deVerdier, 2016).

Childhood Blindness and Visual Impairment Prevalence Studies and Surveillance Systems in the United States

Prevalence studies conducted in economically similar countries as the United States (deVerdier, 2016; Flanagan et al., 2003; Haddad et al., 2005; Nielsen et al., 2007; Ravenscroft et al., 2008; Solebo & Rahi, 2014) indicated a high percentage of children with BVI also had additional disabilities, sometimes significant or severe, and also a high prevalence of neurological vision conditions such as CVI. The following information focused on prevalence studies and surveillance data collections conducted in the United States and they corroborate the results from similar economic level countries around the world.

The following were two examples of population-based prevalence studies that examined the prevalence of four types of developmental disabilities, including visual impairment, but not disabilities that were concurrent. In 1992, Yeargin-Allsopp and colleagues (1992) studied 10-year-old children in five counties in the state of Georgia, two of which included the largest city of Atlanta. The four disability categories included cognitive impairment (originally referred to in the article as mental retardation), cerebral palsy, Deaf/hard of hearing, and BVI. The study did not report prevalence of children with more than one disability, and it was unclear if a child with concurrent disabilities was counted in at least one of the categories or not counted at all. Out of a total of 1,441 children in the sample, 61 children were categorized as BVI with a prevalence rate of .3 to .6 per 1000 (Yeargin-Allsopp et al., 1992). The authors of the study did report that this prevalence rate was consistent with other studies, however it may not have been a true or accurate prevalence of BVI of the population because concurrent disabilities were not included or specified.

The second similar study was longitudinal (covered data over many years) and one of the authors also was a part of the Georgia study (Boyle et al., 2011; Yeargin-Allsopp et al., 1992). It looked at existing data using the parent report survey for children within NHIS used in the United States between the years 1997 and 2008. There was only one question on the survey that asks “Is your child blind or unable to see at all?” This question assumed that children who have some functional vision were excluded from the BVI category since no other questions regarding BVI were asked. Also exploration did not report on children who had concurrent disabilities with BVI or children under the age of three. The results revealed a prevalence rate of BVI at 0.13%

for the years 2006-2008 and a prevalence rate of overall disabilities at 18.2% for 1997-2008. Out of a total of 15,956, only 160 children were categorized as BVI (Boyle et al., 2011). The investigation had many limitations, including a lack of inclusion of children with multiple disabilities and a very narrow definition of BVI, but its greatest limitation was that the size of the sample over 11 years was quite small. But it highlighted the issue of children under 3 and those with additional disabilities concurrent with BVI not being included in some population samples.

Another article reporting data from NHIS was from Cotch et al. (2005). In 2005, Cotch and colleagues reported the prevalence of BVI in children under the age of 18 was 2.5% of the general population according to NHIS. When the data is divided into more specific age groups, the percentages differ depending on age of child; only 1% of children under 6 years of age were reported as being BVI and 3.3% of children aged six to 17 years were BVI. These percentages are much different than the reporting of Yeargin-Allsopp et al. (1992), even though 20 years separate the reporting, and may highlight the challenges to data collection and reporting. These limitations or challenges of the reported data on BVI might be different than the actual number of children with BVI because (a) there is no way to verify accuracies, (b) the information may be incomplete because of an unstandardized definition and measurement of BVI, and (c) low prevalence of any condition may create low reliability for accurate information (Cotch et al., 2005), especially regarding very young children.

Disability Reporting Required by the Individuals with Disability Education Act (IDEA)

When looking at the prevalence of BVI in the school-aged special education population, the U. S. Department of Education, through the National Center for Education Statistics (NCES), reported in 2015 that 0.1% (28,000) of the special education population had visual impairments and 0.2% (132,000) had multiple disabilities (National Center for Education Statistics, 2015). There was no indication of how many of the children with multiple disabilities also had BVI. This suggested that the current data is not accurately capturing the true prevalence of BVI amongst students receiving special education services and the numbers may be much higher than what is reported (Erin, 2007; Kapperman & Love, 1999), considering the high prevalence of children with BVI and concurrent disabilities. This inaccurate count of the population of all children with BVI may have implications for appropriate and responsive services, especially regarding teacher training programs to meet an unrealized or unidentified need.

The data from the U. S. Department of Education and the Office of Special Education Programs (OSEP) indicated a student's eligibility by disability categories but had two significant limitations. First, students aged 6 to 21 were classified by single primary disability only, and second, the data may not be reported consistently across all states affecting the fidelity and validity of the data collected (American Foundation for the Blind Public Policy Center, 2015a). From 1976 to 2012, the number of children with BVI decreased by 13,000: from 38,000 in 1976-77 (National Center for Education Statistics, 2015) to 25,567 in 2014 (U. S. Department of Education, 2015), while the numbers of children identified as multiply disabled have almost doubled from 68,000 in

1980-81 to 132,000 in 2011-12 (National Center for Education Statistics, 2015). It was highly likely that children who have concurrent BVI and additional disabilities were counted in other categories and not the BVI category, such as developmental disabilities, multiple disabilities, other health impaired, Deaf/hard of hearing, or traumatic brain injury, which directly implied an inaccurate count, specifically an under-count, of all children with BVI (Kapperman & Love, 1999).

Regarding children under 3, IDEA Part C, the early intervention (EI) for children aged birth to three portion of the law, does not require reporting of disability categories as part of its eligibility requirements, as does Part B for students aged three to 21 (Bruder, 2010). Eligibility to Part C, or EI services, is defined by an age range rather than disability etiology (Bruder, 2010). For example, as eligibility is based on degree of overall developmental delay and children with BVI who may be receiving specialized visual impairment services, are not "counted" as BVI or tracked until they enter school and Part B services. In 2006, there were 282,733 children in Part C services compared to 701,949 students enrolled in special education services in Part B. The large numbers of children in Part C compared to lower numbers in Part B may have indicated great variation in eligibility criteria between Part C and Part B. Or this discrepancy may possibly have indicated an increase of children with disabilities and the great diversity of the overall special needs population (Bruder, 2010), which was not being uncovered with child counts involving no disability category at all.

Another way children (aged birth to three) and students (aged three to 21), both with BVI, in the United States are counted is through the Federal Quota Registry at the American Printing House for the Blind (APH). The registry counts all children aged birth to 21 who are blind or visually impaired and specifically meets, or functions at, the definition of blindness including those with multiple disabilities or disabilities concurrent with BVI. In 2013, there were 60,383 students aged three to 21 and 4,501 children aged birth to three, which equals to approximately 1% of the special education population (American Foundation for the Blind Public Policy Center, 2015a). The figures from APH almost doubled the number of children with BVI accounted for by OSEP, which also greatly indicated an undercount of children with BVI by the US Department of Education, particularly when children with additional disabilities were possibly not included in the BVI category (Kapperman & Love, 1999).

Two other data sets also indicated there may be an undercount of children with BVI. First, the National Survey of Children with Special Health Care Needs in 2009-10 reported that 4.4% of infants and toddlers had a little difficulty seeing and 2.5% had a lot of difficulty seeing. When added together, the assumption was 6.9% of infants and toddlers with special health care needs have some level of difficulty with seeing (American Foundation for the Blind Public Policy Center, 2015b). This prevalence percentage roughly aligns, though lower, with Nielsen et al. (2007), who reported in Denmark that 10.5% of children with developmental disabilities also had BVI.

Second, the data from the National Child Count of Children and Youth who are Deaf Blind (NCDB) indicated that in 2014, there were 9,454 children with a dual sensory loss (both hearing and vision disabilities) and 552 were infants and toddlers (American Foundation for the Blind Public Policy Center, 2015b). Since 90% of these children had additional disabilities they may not have been included in the BVI OSEP data. There was a marked difference between OSEP's number of 2,000 students who are classified as deaf-blind (National Center for Education Statistics, 2015) in 2011-12, even when accounting for 552 of them being under the age of three, demonstrated another indication of an undercount of all children with BVI.

Studies Involving Schools for the Blind in the United States

Schools for the blind have been found to be a convenient population to study the prevalence of BVI, however there were some limitations to both the methodology and the resulting data. A study in 1999 highlighted the underrepresentation of students with additional disabilities concurrent with BVI. Steinkuller et al. (1999) conducted a study to evaluate data from world literature and data from schools for the blind in United States to do a comparison. They found access to information very difficult as only 68 out of 128 schools for the blind in United States responded. Also out of 68 schools in the United States, only 20 schools, had useful data to obtain a sample size of 2,553 students with BVI. Other methodology limitations of their study, in addition to the lack of response, might also explain the lack of response: Each school had different enrollment criteria and most students had more than one cause of blindness or additional disabilities. Also many schools for the blind did not keep detailed or consistent records on students therefore were unable to share their information with the researchers (Steinkuller et al., 1999).

Steinkuller et al. (1999) was not able to establish a United States prevalence estimate because not all students with BVI attend a school for the blind, and the overall response rate was low. However, the data of 2,553 students found by Steinkuller et al. (1999) aligned with other studies on visual etiology worldwide for developed or economically rich counties, such as Solebo and Rahi (2014), Lewerenz et al. (2016), and

Wall and Corn (2004). The ranking of etiologies had CVI as the most prevalent etiology, with ROP as second, and OHN a close third (Steinkuller et al., 1999).

A recent prevalence study of specific visual conditions of students enrolled at the Oklahoma School for the Blind in 2014 also indicated ROP and ONH as leading causes of visual disabling conditions (Lewerenz et al., 2016). The inquiry compared the student enrollment at the Oklahoma School for the Blind in two separate years, specifically the years of 1987 and 2014. While no statistical significance was found for differences in ages, gender, and visual acuities between the students in the two separate years, they did find significance in the visual conditions. In 1987, ROP was one of the top conditions, yet in 2014, ROP had almost doubled from 10% in 1987 to 20.4% in 2014. Two visual conditions, ONH and CVI, were not even mentioned in 1987 and in 2014, both were not specifically reported as individual or distinct visual conditions, but rather within other categories. ONH was included in the “congenital malformations” category and comprised 24.7% of that category. CVI was included in the “other” category and comprised of 5.4% of that category. While categorizations of visual conditions differed in the two years examined, the authors found it remarkable that ONH and CVI were not mentioned and indicated a possible increase in prevalence since 1987 (Lewerenz et al., 2016).

In 2004, Wall and Corn examined the prevalence of students with BVI in the state of Texas, as well as an examination of the characteristics of this population. Their sample consisted of students enrolled in preschool up to age 22 in both Texas public schools and the Texas School for the Blind and Visually Impaired (TSBVI). They identified 6536 students, or 0.16% of the general school aged population, with visual impairments in year one (2000-01) and 6950 students, or 0.17%, in year two (2001-02). They also found that 67.2%, in both years, qualified for APH federal quota registry and 65% of the students were also reported as having additional disabilities, even though 58% of the students had BVI as their primary disability. Another surprising statistic uncovered in their analysis was 25% of the students were reported as being blind, but only 7% of students in the state used braille as their primary learning media, which may also indicate a large number of students with multiple impairments concurrent with BVI. Even though Wall and Corn (2004) reported that the prevalence rate in Texas was consistent with other prevalence rates and were confident they captured all the students identified as BVI in the state, they also reported that this number may still be an under-representation of the true characteristic nature of the population due to different measurement criteria of BVI between multiple agencies or schools (Wall & Corn, 2004).

Another study mirrored the results from the Texas study (Wall & Corn, 2004), even though almost 20 years apart, regarding the presence of additional disabilities in children with BVI. The National Plan for Training Personnel to Serve Children with Blindness and Low Vision (NPTP) was a joint project comprised of the Division of Visual Impairments (DVI) of the Council for Exceptional Children (CEC), the American Foundation for the Blind (AFB), and the Association for the Education and Rehabilitation of the Visually Impaired (AER). This collaborative group looked at children ranging in age from birth to 21 from a random sample of 17 states in 1998. The study's grand total is approximately 93,600 children with BVI and specified (a) 32,700 (35% of the sample) children had a single disability of BVI, (b) 50,100 (53% of the sample) children had one additional disability concurrent with BVI, and (c) 10,800 (12% of the sample) children were considered deaf blind (Kirchner & Diament, 1999).

Babies Count: The National Registry for Children Aged Birth to Three in the US

One way to obtain a true prevalence, as well as obtain an accurate portrayal, of young children with BVI in the United States is to identify the BVI as early as possible through a coordinated system of national data collection. Cotch et al. (2005) highlights the need for early identification due to reports that indicated only 36.3% of children under the age of 6 have their vision tested by an eye care professional (Cotch et al., 2005). This lack of early screening for vision problems did not meet the Vision Health Initiatives set forth by the Center for Disease Control (CDC), which included the following: (a) promote eye health and prevent vision loss, (b) improve health of those with vision loss, (c) reduce vision and eye health related disparities, and (d) integrate vision health with other public health strategies (Cotch et al., 2005). A public health strategy includes a consistent and accurate surveillance systems for BVI. The goal of surveillance is not only to count children with BVI, but also to identify the diverse characteristics of the population, which includes the presence of additional developmental disabilities.

To date the Babies Count project is the only national database used to track the identification of visual etiology and characteristics of children aged birth to three in the United States (Hatton et al., 2013). The current Babies Count data collection form, completed by educational professionals of children with BVI who provide EI services, gathered epidemiologic information about children including visual etiologies, dates of critical events such as diagnosis of visual condition and referral to services, presence of additional medical and developmental issues, types of EI services being provided, and transitional information when the child leaves EI services. Also family demographic information was gathered such as ethnicity, language, age of parents, and parental education levels. It used both the medical and social models for gathering information as suggested by Hendershot et al. (2006), as it recorded a baby's medical and vision condition as well as functional visual and developmental behaviors.

Babies Count started in 1995 with a report of the first year data analysis in 2001 (Hatton, 2001). This first year report, comprised of data from January 1998 to June 1999, was able to identify the three top vision etiologies as CVI, ROP and ONH based on data from 406 children, consistent with other studies examining common vision etiologies of similar economically advantaged countries (Kong et al., 2012; Solebo & Rahi, 2014; Steinkuller et al., 1999). This first year report also demonstrated great variability in developmental abilities and delays amongst the children indicating an inability to generalize across the sample (Hatton, 2001).

The most recent data analysis and published article on Babies Count (Hatton et al., 2013), included 5,931 children in 28 states from January 2005 to April 2011 and indicated the top three eye disorders continued to be CVI, ROP, and ONH as they were in previous analysis using the Babies Count database (Hatton, 2001; Hatton et al., 2007). It appeared that ROP and ONH are nearing the same in prevalence rate, and again may be due to ROP declining with medical advances (Kong et al., 2012).

One notable change in the BVI etiology trend appeared to be the increase of multiple disabilities in connection with ROP, as many more babies are born earlier, smaller, and sicker, which may lead to additional disabilities and a combination of CVI, due to neurological issues concurrent with mild ROP. Hatton et al. (2013) demonstrated that 68% of the children under the age of three with BVI in the 2007 analysis had multiple disabilities, with 65% in the 2013 analysis. The prevalence of multiple disabilities in all children with visual impairments was another trend highlighted, as all three top vision conditions were reported with large numbers of additional disabilities. This revelation highlighted the need for early identification and referral to specialized visual impairment support within EI services for children with BVI and additional disabilities, due to the greatest developmental need within this population.

In addition to securing accurate and current information on the prevalence of BVI in young children, the mission of the Babies Count project was to develop, implement, and to continue to improve responsive specialized early supports for young children with BVI (Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007). In order to measure the ability to provide responsive specialized early support services set by the National Agenda (Huebner et al., 2004), data must be obtained to evaluate responsiveness and timely delivery of services. Babies Count gathered data on the date a child was diagnosed with a visual condition linked to a visual impairment and also the date a child was referred for specialized visual impairment services within the EI system. The time between these two data points indicated responsiveness of the EI system and accessibility to specialized visual impairment services, which are appropriate and necessary for a child with BVI.

The 2007 analysis included 2,155 children from 29 states between January 2001 and December 2004. The average age of diagnosis was at 5.5 months of age; children with ocular structure abnormalities were diagnosed the earliest at 1.5 months of age and children with CVI were diagnosed the latest at 7.6 months of age (Hatton et al., 2007). In the 2013 analysis of data from January 2005 to April 2011, which included more children than in 2007, the average age of diagnosis was 4.9 months; children with ocular structural abnormalities were again diagnosed earliest at 2.2 months of age and children with CVI were again diagnosed the latest at 6.8 months. This similarity proved to be statistically significant (Hatton et al., 2013).

According the 2013 reporting of Babies Count, the average age of diagnosis of BVI was 4.9 months of age and the average age of referral to specialized visual impairment services was 10.5 months (Hatton et al., 2013). These results implied a gap of 5.6 months that these babies and their families needed to wait for services. This gap is significantly higher than the standard of 30 days set by the National Agenda (Huebner et al., 2004). As with age of diagnosis, the age at referral was also different depending on the eye condition. Children with ocular structural abnormalities were the first to be referred to specialized visual impairment services, at 6.9 months after being diagnosed at 2.2 months old, and children with cortical visual impairment were more likely to be referred later, at 11.1 months of age after being diagnosed at 6.8 months old. Children with ROP had the longest gap between diagnosis (2.8 months) and referral (10.1 months), with a 7.3 month delay or wait for services. There may be many reasons for this, and one potential reason may be children with ROP typically spend more time in the hospital after their premature birth than their peers (Hatton et al., 2013).

While Hatton and colleagues (2013) examined the age of diagnosis and referral through only one variable, the child’s visual condition, other variables may also contribute to both the expedience and delay in referral to specialized visual impairment services after the diagnosis. For instance, the referral source may be a variable worth examining, as well as geographic region, parent education level, presence of additional disabilities, language or ethnicity to name just a few. Hatton and colleagues (2013) did report general EI providers referred 44.8% of the sample to specialized vision services, and 37.6% of the sample were referred by a medical professional. However, no additional information was reported regarding type of provider or medical professional, or if these providers referred within different timelines. This information may be critical to fully examine a responsive system of Child Find.

Limitations in the Existing Literature

This review of the literature highlighted some very important limitations regarding the data in existence to demonstrate the true prevalence of BVI in young children and an identification of the characteristics of the population. First, true prevalence of BVI in children was grossly underestimated due to the diverse definitions of BVI and many existing databases not including co-concurrent disabilities. For example, the federal regulations for the U. S. Department of Education regarding OSEP classifications of children receiving special education services through IDEA Part B, indicated that each child was counted in only one category of eligibility (American Foundation for the Blind Public Policy Center, 2015a). Children who are BVI with concurrent disabilities, such as multiple impairments, may not be included in the BVI category (Kapperman & Love, 1999). Other surveillance systems or studies were also not detecting, and subsequently not defining, the diversity in the population of children with BVI, especially with the large numbers of children who also have additional disabilities.

Second, there was very little prevalence data available for young children with BVI, as most surveillance systems and prevalence studies were geared to adults not children, especially very young children under the age of 3. While young children might be difficult to assess for visual function and identification of developmental delays, information was still available and useful as demonstrated by Babies Count and others that document the diverse characteristics of the population of young children with BVI.

Even though few surveillance systems existed for children with BVI, and children with multiple disabilities were not typically included, there did seem to be some consistency amongst the various studies that did focus on children regarding the characteristics of the population. Those similarities specifically included (a) the presence of additional disabilities (deVerdier, 2016; Haddad et al., 2005; Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007; Nielsen et al., 2007), (b) the cause of BVI, especially a neurological component rather than an ocular component as the leading cause of BVI (Flanagan et al., 2003; Lewerenz et al., 2016; McClelland et al., 2007; Ravenscroft et al., 2008; Solebo & Rahi, 2014; Steinkuller et al., 1999), and (c) economics as one possible factor of BVI and differences in BVI vary between economically advantaged counties and disadvantaged (Gilbert et al., 2005; Kong et al., 2012; Ravenscroft, 2016; Solebo & Rahi, 2014). The trend of a changing nature of BVI and presence of additional disabilities was an explicit concern as it dramatically changes the way services should be provided, considering the developmental needs are greater in these children, but also the material pre- and in-service teachers should know and their training.

It was still unclear if the data illustrates a true trend, since most surveillance systems, including Babies Count, did not capture all children with BVI. Babies Count included all children enrolled in specialized visual impairment EI services, but not all states participated and not all educators completed surveys on all children. Babies Count still appeared to be a good sample of the population, although the sample was not random and was considered a convenience sample. The same could be true for studies using schools for the blind as samples of the overall population for children with BVI. Though the sampling procedures greatly diminished the reliability of the information, the consistency amongst all of them did promote some validity. While it was not completely reliable as a true prevalence study, Babies Count defined the diversity and heterogeneous aspect of the population of children under the age of three with BVI, including the responsiveness of and accessibility to specially designed support programs.

More research is needed within both populations of visual impairment and developmental disabilities with young children to identify the differences, as well as the similarities, shared by both groups of children. First, the differences and similarities within the population might be related to the racial, ethnic, economic, or geographical differences regarding BVI. While these variables are widely collected and available, they are not available related to BVI. These variables may create potential barriers and a great impact on the identification and referral for specialized services to children with BVI (Kirchner & Schmeidler, 1999), which make them worthy of investigation. An example was the NHANES and NHIS surveys that include race, ethnicity, education, and economic factors to examine if disparities exist in the prevalence of BVI amongst these groups, however it was also limited through inclusion of data to age-related BVI with adults only (Zhang et al., 2012). Disparities were found to exist between racial and economic groups, but it was still unknown or questionable regarding the reliability of this data based on self-report procedures (Zhang et al., 2012) or even if the information could even be generalized to children.

Second, there was no consistency between surveillance systems and prevalence studies, specifically how each system defined BVI and unstandardized data collection procedures. Longitudinal studies may be the key to this reliability, but consistency amongst surveys is then also needed for accurate comparisons (Crews et al., 2012; Hendershot & Crews, 2006; Kirchner, 1999b). Current surveillance methods and questions differ, so no uniformity, or harmonization, existed to combine or compare data, even among longitudinal studies, created great disparity amongst data and results. Prevalence data could be used to track changes or trends, but since the results varied so much it is hard to know if they were really trends due to the factors related methodology rather than actual changes or trends (Kirchner, 1999b).

While this literature review highlighted the brief knowledge base of the visual and developmental needs of children, the changing trends of visual etiologies, and the characteristics uncovered within this diverse population are important to note. The information gathered thus far from Babies Count is valuable to the field, both EI and educational services mandated through IDEA, even though it had considerable limitations due to a lack of reliability measures and the lack of all states “counting” their babies enrolled in vision services within their EI systems. Therefore, it was not known at this time if the information is a true generalization of the population of young children with VI, however, it does seem to align to the gathered information about visual prevalence and types of etiologies in other developed and higher income countries such as the Scotland, Sweden, the United Kingdom, Finland, and Canada (deVerdier, 2016; Gilbert et al., 2005; Kong, et al., 2012; Ravenscroft et al., 2008).

Finally, this review highlighted the need for a public health approach to understand the population in order to “fix” a fragmented system. This approach includes establishing an accurate and useful definition BVI and the intentional use of the information to improve the support for the needs of young children (DiStefano, Huebner, Garber, & Smith, 2006; Kirchener & Schmeidler; Zhang et al., 2012), including the training and preparation of educational professionals for children with BVI. Also included in this public health approach should be strategies for early vision screening to meet the CDC’s Vision Health Initiatives and early referral procedures for support services of young children with BVI in accordance to the National Agenda. This comprehensive and coordinated system for Child Find, including the determination of eligibility and access to appropriate supports (Macy et al., 2014; Speedwell et al., 2003), is needed. It is very critical to utilize surveillance data not only to provide epidemiologic information about the population of young children with BVI, but also to measure the effectiveness of early identification and referral systems to assure that children and families are receiving support within agreed upon timelines (Farel et al., 2003; Miller et al., 2008), such as those recommended by the National Agenda (Huebner et al., 2004).

A public health approach includes the overall need for accountability in tracking this information for the improvement of EI services for young children with BVI, especially as related to increased responsive of accessibility of specialized visual impairment services. An example are surveillance data systems that not only address visual and medical characteristics, but also those which could give information regarding potential barriers for early identification and referral to support services, with the goal of reducing the wait times for services (Miller et al., 2008). Babies Count is a surveillance system that gathers this information and may provide the field with this accountability, if it were utilized consistently amongst all states and programs that provide early support services to young children with BVI and their families. As Kirchner (1999a) advised, it is critical that any surveillance system designed to measure the prevalence of children with BVI, including the diversity of characteristics among them, and are intentional in their use of the information to better the systems designed to support them. Documentation of the implementation of this information as well as the accountability in this endeavor is needed.

Conclusion

The purposes of surveillance systems or studies on the data of prevalence, especially as it relates to early identification for EI services to best meet the needs of children and families, are to (a) define a population and its characteristics, (b) evaluate the effectiveness of services and interventions, and (c) provide a rationale for funding requests (American Foundation for the Blind Public Policy center, n.d.; Boyle et al., 2011; Crews et al., 2012; Kirchner, 1999a, 1999b; Kirchner & Diament, 1999; Yeargin-Allsopp et al., 1992). This literature review reflected that there are challenges to conducting prevalence studies and that the true population of young children with BVI may not be fully understood. This misunderstanding was not isolated to prevalence numbers (how many young children have visual impairments), but also the heterogeneous nature and diversity within the population as many studies do not include children with concurrent disabilities, nor do they include children under the age of three. Also the educational surveillance system mandated by IDEA Part B and Part C through the U. S. Department of Education and OSEP are not accurately counting all the children with BVI and many are left out (American Foundation for the Blind Public Policy Center, 2015a). Regardless of the challenges presented, epidemiological information regarding the prevalence of BVI in children is critically important for the field of education for the BVI, because if the characteristics or true needs of the population are known, then service providers/teachers can be adequately prepared to meet the specified needs (Bruder, 2010; Kirchner & Diament, 1999). Educational systems are able to meet the needs of these children and their families if proper identification is completed, documented, and accessible for use in policy development regarding both educational programs for children and the training programs for their service providers/teachers (Belcher, Hairston-Fuller, & McFadden, 2011).

True prevalence may not be enough. Kirchner (1999a) stressed that there may be a "danger in looking for one true prevalence number by oversimplifying how to count people as visually impaired" (Kirchner, 1999a). This may be especially true for children, as BVI is too complex and diverse to simplify educational needs based on a number. Counting is not enough and information regarding individual characteristics is needed to accurately plan for needs (Hatton, 2001; Kirchner & Diament, 1999). Also, the shortage of service providers/teachers indicated by Kirchner and Diament (1999) highlighted the difference between the size of the need for services and the size of the supply of providers. The apparent undercount of children with BVI, as well as the misunderstanding of the diversity within the population, may be worsening the shortage for knowledgeable and well prepared educational service providers/teachers for children of all ages with BVI (Kirchner & Diament, 1999). It may be difficult to prepare teachers, when a true account of the population of children with BVI, and the perceived need of children with BVI and additional disabilities, is not fully known or understood.

The re-authorization of IDEA in 2004 established reporting requirements for 14 benchmark indicators for effectiveness of the interventions in Part C services, and "the data collected thus far demonstrate that early learning and development is positively affected by intervention" (Belcher et al., 2011). Additionally, the benefits of EI include: (a) early identification means early support to compensate for risk of delays; (b) families are supported which leads to empowerment, engagement, and competencies in parenting; and (c) public education benefits from a potential for reduced cost (Bruder, 2010). For the child with BVI, these types of support and benefits are of equal importance with a focus on how vision, or lack thereof, influences the impact on overall development. It is also assumed that early identification of vision loss, or any other suspected disability category, leads to early support and therefore increased benefits (Bruder, 2010; Solebo & Rahi, 2014). Parents also report the need and desire for getting information as soon as possible regarding their child with BVI (Speedwell et al., 2003). The earliest a parent receives information regarding their child's BVI diagnosis and availability of support services, the more a parent is likely to experience positive accommodation and empowerment over one's perceived situation, including a nurturing parental relationship with their child.

Part C of the Individuals with Disabilities Education Act (IDEA) for children aged birth to 3, agrees that early identification, referral, and implementation of early intervention services and supports is important and mandates a 45 day timeline between referral and eligibility determination with creation of an IFSP (Individuals with Disabilities Education Act, 2004). This 45-day mandate does not refer to specialized visual impairment support services, specifically, for children with BVI, nor any other specialized service, and is a general guideline for all children eligible for Part C services regardless of their unique needs. Therefore, the National Agenda for the Education of Children and Youth with Visual Impairments, Including those with Additional Disabilities, has set the standard for timely delivery of services. Goal #1 states: "Students and their families will be referred to an appropriate education program within 30 days of identification of a suspected visual impairment" (Huebner et al., 2004). This is the standard the field of education for BVI should maintain for children of all ages, but especially for children under the age of 3, given the critical needs of immediacy at this young age.

Based on the data obtained by Babies Count, the average time gap between diagnosis of BVI and referral for specialized vision services was 5.6 months (Hatton et al., 2013), which was significantly higher than the 30-day standard set by the National Agenda (Huebner et al., 2004). It may be critical to examine the potential barriers to this standard being met. Macy et al., (2014) investigated the eligibility phase of the Child Find process and found a few systematic barriers, including a general lack of recognition of true needs of children and families. These include (a) a diverse variability of programs and their eligibility processes to identify children, (b) an inappropriate and inconsistent use of screening tools, and (c) no accountability in measuring program effectiveness as programs are not monitoring themselves. For children with BVI, a screening tool is important, but the knowledge base of general early intervention service providers about the unique needs of children with BVI may also be a barrier to responsive services, given that 44.8% of EI providers referred children with BVI to specialized visual impairment services (Hatton et al., 2013). Most critical is the “wait and see” attitude amongst medical professionals, who may not understand the benefits of EI (Macy et al., 2014), and who comprised only 37.6% of referral sources of children with BVI to specialized vision services (Hatton et al., 2013).

Mott & Dunst (2006) proposes the use of presumptive eligibility to speed up the eligibility process. Presumptive eligibility is the use of a diagnosed mental or physical condition, such as BVI, for eligibility to EI services, which accelerates the lengthy, complex, and unnecessary process of a multi-disciplinary evaluation process. When Mott and Dunst (2006) researched the use of presumptive eligibility, they found that the eligibility process took longer than 45 days for 40% of children referred for EI services, and 66% of these children could have been eligible based on presumptive eligibility, such as a child with BVI. Overall the use of a complex evaluation procedure comprised 85% of all the late cases in their sample (Mott & Dunst, 2006). Even though their study did not specify presumptive eligibility categories for children with BVI, it is a general look at the lack of responsiveness to the accessibility of EI support and services for children and families with disabilities that needs to be highlighted.

The overall goal of a responsive service delivery is early identification of a medical eye condition that signifies a highly possible impairment of visual ability and the accessibility to specialized visual impairment supports within the EI system. Babies Count is one example of a surveillance system to give a data driven direction to the field of education for young children with BVI in the United States, to not only define the population to be served and identify the characteristics of children with BVI, but also to measure the responsiveness of the accessibility and implementation of services and supports.

CHAPTER III

METHODS

Design

This study was a quantitative investigation utilizing a secondary database, specifically the first year of a revised data collection process, to provide a description of a sample within the population of young children with blindness and visual impairment (BVI). This research study replicated a portion of the data analysis and the research questions from the previous analyses of the Babies Count database (Hatton, 2001; Hatton et al., 2007; Hatton et al., 2013), including a descriptive analysis of the most prevalent eye conditions, presence of additional disabilities, and the time gap between age of diagnosis of BVI and the age of referral to specialized visual impairment services within Early Intervention (EI) programs. The findings from previous analyses were compared with current findings. More specifically, the exploration also used the Babies Count database to analyze the responsiveness, or timely delivery, of EI visual impairment specific services to support young children with BVI and their families by analyzing more closely the specific variables possibly contributing to the delay in referral for services.

The current study followed recommendations from previous studies utilizing the Babies Count database (Hatton et al., 2013; Hatton et al., 2007) for further research to examine more closely the variables potentially related to responsive and timely delivery of services. Previous research identified a significant time gap between the age at which a child is diagnosed with a visual impairment and the age at which children are referred for specialized visual impairment services within EI. An average of 5 months has been identified as the delay between diagnosis and referral to services (Hatton et al., 2013; Hatton et al., 2007), yet the potential reasons or variables that may contribute to a delay, beyond differing eye conditions, have not yet been identified. The National Agenda for the Education of Children and Youths with Visual Impairments (Huebner et al., 2004) defined the standard for timely delivery of referral to services to be within 30 days after the diagnosis of a medical condition that leads to a visual impairment. A detailed analysis of potential variables may allow the field of EI for children with BVI to improve the quality of responsive and timely service delivery by identifying factors related to the gap to assist with program development.

The research questions answered in this study were:

Q1 In the last year, what are the most prevalent child, family, and service characteristics of infants and toddlers with blindness and visual impairment, including
  a. What is the gap between age of diagnosis of visual impairment and age of referral to specialized vision services?

Q2 What is the relationship among child characteristics, family characteristics, and service characteristics and
  a. age of diagnosis of blindness or visual impairment; and
  b. age of referral to specialized vision services?

Q3 Which variables predict the age of diagnosis of blindness or visual impairment and age of referral to specialized vision services?

Q4 How do the results from this study compare to the results reported in the 2013 Babies Count analysis (Hatton et al., 2013), including
  a. Trends in child and service characteristics; and
  b. Differences that may be relevant for EI service providers?

Participants

The participants in the Babies Count database were infants and toddlers between the ages of birth and 36 months who had been identified as blind or visually impaired and received early intervention (EI) services, including specialized visual impairment services. The participants' identities were anonymous rather than confidential, as no names were used but each data collection form was given an identifying number code. This unidentifiable coding procedure enabled the database to track two data collection periods per child, an entry and exit to specialized vision support services, yet protect recognizable information to follow the actual child at the local agency level.

The data were collected through individually registered agencies, both public and private, that provided specialized visual impairment services within EI programs across five states. The states represented in the sample included California, Maryland, New Mexico, Utah, and Washington. Educational professionals employed by agencies in these five geographical locations completed a Babies Count data collection form in cooperation with the families of the children. The professionals were specialized visual impairment service providers including teachers of students who are visually impaired (TVI), state certified orientation and mobility specialists (O&M), or other EI providers employed by a specialized visual impairment service agency.

Because professionals obtained data with the cooperation of families, the evaluation of the current database was confronted with missing data. A very important component of the data collection process was the respect for a family's desire not to answer a question they were not comfortable in revealing. Also, many children may have lived in an alternative family situation, such as a foster home, where some information may not have been available.

The sample in this study was obtained through a secondary database and was considered a convenience sample, therefore may have resulted in a sample bias. The sample bias was acknowledged in two ways. First, the sample was obtained by specific and specialized agencies serving children with BVI that are motivated and very interested in the Babies Count project. These agencies did not represent all agencies across the United States. Previous analysis using the Babies Count database included up to 28 states participating (Hatton et al., 2013). It was not possible to calculate the non-response rate within participating states as not all agencies providing specialized visual impairment services participated in the registry project. Second, the sample of children included also did not represent, or include, all children with BVI; therefore a true generalization to the entire population may not be actualized. However, the Babies Count registry project has accumulated data for more than 8,000 infants and toddlers with BVI in its 20 years of existence and is considered the largest database of its kind in the United States (Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007). The study included a sample size of 588 infants and toddlers with BVI.

An approval from the Institutional Review Board at the University of Northern Colorado was received in the expedited category. The approval letter is provided as Appendix C.

Data Source and Instrumentation

Babies Count is a national registry project to collect epidemiologic and demographic information that started in 1995 to advise the field of education for children with BVI about medical and developmental characteristics of children with BVI aged birth to 36 months. Additionally, the database included information for both family and EI services, including those specialized to support children with BVI. Critical epidemiologic and demographic data, including the leading causes of BVI, informs the field of education for children with BVI, as well as EI programs, teacher personnel preparation programs, and the medical community in order to meet the current and future needs of this diverse population (Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007).

A taskforce called The Registry of Early Childhood Visual Impairment Consortium Group (RECVICG) was formed within the 1995 International Preschool Seminar meeting, which is a collaborative meeting of professionals from specialized vision service agencies throughout the United States and Canada who provide early childhood educational services for children with BVI. The RECVICG developed a surveillance system of collecting demographic data on children with BVI, including the visual and medical diagnoses, family characteristics, and the early intervention services received. This system was modeled originally after a data collection process established by the Blind Babies Foundation, an agency that provides EI support services to children with BVI and their families in northern California. The Babies Count project has impacted the fields of EI and education for children with BVI by creating a centralized national registry of children that clearly defines this population of young children who are blind or visually impaired where no other exists.

Over the past 23 years of the registry, the project has had many transitions. Appendix A describes the history of the Babies Count project through a timeline of its beginning to its most recent upgrade and revision. The database was housed the longest, for 13 years, at the American Printing House for the Blind (APH) in Louisville, Kentucky, but the project was recently transitioned to the New Mexico School for the Blind and Visually Impaired (NMSBVI). Assisting in the transition was the 2013 International Preschool Seminar meeting participants who created another taskforce, similar to RECVICG, comprised of committed professionals in the field of EI for children with BVI from the states of Arizona, California, Colorado, New Mexico, Kansas, Kentucky, and Missouri, reflecting a national effort to the continued mission of the project. This taskforce worked together to revise the data collection form, and also developed a new electronic database with an online submission process to bring the project in alignment with today's technology. Appendix B is a comparison chart of the old data collection questions and the new questions on the recent revision of the data collection form to highlight the variable numbers for the current study.

The Babies Count database gathered epidemiologic and demographic information about children and their families including information about their vision and medical diagnosis, presence of additional disabilities, and types of early intervention services, specifically visual impairment related specialized services. Educational professionals for children with BVI, such as teachers of students with visual impairments (TVI), state certified orientation and mobility specialists (O&M), and developmental specialists employed by a specialized agency providing EI support services for children with BVI, gathered information through the completion of the 37 question data collection form with cooperation from families. The data collection form was completed at the child's entry to specialized visual impairment EI services and then again at exit. Appendix D is the actual data collection form and questions for the Babies Count registry project.

Data were collected through an online submission process that directly enters the information into a national database through the website www.babiescount.org. The database was designed to organize data into geographical locations according to state and also individual agencies within each state. Each state had access to the represented state's data through a designated state lead agency. Also each individual agency accessed its own data at a local or agency level. National, state, and local accessibility allowed the information from each state and individual agency to be used for individual programming decisions, including program development and funding requests, as well as collectively at a national level. The New Mexico School for the Blind and Visually Impaired (NMSBVI) is the home of the Babies Count database, and it shared the raw data with the researcher.

Data Analysis Procedures

Though the database included data collection since 1995, this investigation focused on data gathered for the first year of the newly revised data collection form and database, which was from March 2016 to May 2017 and included 14 months of data.

Q1 In the last year, what are the most prevalent child, family, and service characteristics of infants and toddlers with blindness and visual impairment, including

  a. What is the gap between age of diagnosis of visual impairment and age of referral to specialized vision services?

The first process included descriptive statistics to answer research questions one for all variables in the study. Appendix B describes all the variables in the study and compares the numerical assignment of the variable from the new and previous survey. The variables were categorized into three separate groupings. The first group were characteristics specific to the child including vision conditions, additional medical conditions, and the presence of other developmental delays. The variables related to child characteristics are listed in Table 1.

Table 1

Variables Related to Child's Vision, Medical, and Developmental Delays

Child characteristic variable	Old survey variable #	New survey variable #
Gender	2	1
Date of birth	5	2
Birthweight	8	3
Gestational age at birth	6	5
Multiple birth	9	6
Right eye primary condition	18	14
Right eye additional condition(s)	19	15
Number of right eye additional	-	-
Left eye primary condition	20	16
Left eye additional condition(s)	21	17
Number of left eye additional	-	-
Etiology of vision diagnosis	33	18
Visual optics needed	24	20
Other health/medical conditions	34	21
Number of other health/medical conditions	-	-
Other developmental delays	34	22
Number of domains delayed	-	-
Level of vision	-	23
Level of support need	-	24
Primary learning channel	-	25

The second group included characteristics related to the family and parents/caregivers of the child. Variables included ethnicity and primary language of the family whom the child lives with, and the identification of the primary caregiver of the child. Additionally, individual information for the mother and father of the child was gathered such as ages of the parents at the child's birth and their level of education. The variables related to family characteristics are listed in Table 2.

Table 2

Variables Related to Child's Family

Family characteristic variable	Old survey variable #	New survey variable #
Ethnicity	3	4
Number of ethnic groups	-	-
Mom age at birth	13	7
Dad age at birth	14	8
Child's caregiver (who child lives with)	15	9
Primary language	16	10
Parent education	17	11

The third group included variables related to the specialized vision services the child received within the early intervention program. Variables included age of the child at the time of diagnosis of visual impairment, age at the time of referral, referral source, and types of specialized vision services. The variables related to the early intervention services are listed in Table 3.

Table 3

Variables Related to Child's Early Intervention Services

Service characteristic variable	Old survey variable #	New survey variable #
Zip code (state)	4	26
Age at visual diagnosis	10	13
Months between diagnosis and referral	-	-
Age at referral	11	27
Days between referral and enrollment	-	-
Age at enrollment	12	28
Referral source	36	29
Early intervention vision service provider	39	30
Frequency of vision service	-	31
Location of vision service	38	32
Other early intervention services	40	33
Number of other early intervention services	-	-

A few variables were created from other variables. For example, the variable of additional visual conditions consisted of more than one and in some cases many different visual conditions per individual. The variable of "number of additional eye conditions" was created to indicate how many eye conditions were present. The same type of variable was created for ethnic groups, other medical/health conditions, developmental delays, and other early intervention services. Other variables were created to indicate the age of the child, rather than the date of occurrence, as in the date of diagnosis, referral, and enrollment. Also, the variables for "months between visual diagnosis and referral" and "days between referral and enrollment" were created from the dates presented in the database. Additionally, the variables included both categorical and continuous variables. The categorical variables were analyzed according to their frequency and percentage of the total. Continuous variables were analyzed according to mean, variance, standard deviation, minimum, and maximum. Additionally, if a variable had missing or unknown values they were reported as such.

Q2 What is the relationship among child characteristics, family characteristics, and service characteristics and
  a. age of diagnosis of blindness or visual impairment; and
  b. age of referral to specialized vision services?

Q3 Which variables predict the age of diagnosis of blindness or visual impairment and age of referral to specialized vision services?

For both research questions two and three, multivariate statistical analysis of regression was used to determine relationships between groups of variables and prediction or explanation of the variable's contribution to both the age of diagnosis and age of referral. For research question two, the relationships between the dependent variables (age of diagnosis and age of referral) and the independent variables (child characteristics identified in Table 1, family characteristics identified in Table 2, and service characteristics identified in Table 3) were determined using Analysis of Variance (ANOVA) procedures to identify if a statistically significant difference existed within an individual variable group to indicate a relationship. Also, a Pearson's correlation was identified in each variable group. Identifying and defining the relationships between the dependent and independent variables did not only justify research question three, but also assisted in identification potential strategies for the improvement of quality of service delivery to children and families, specifically the improvements of responsiveness and accessibility to services. The analysis was conducted with one variable at a time entered into the regression equation to determine each characteristic's regression coefficient.

A multiple regression was preformed to explain which predictor/independent variable, or variables, contributed most predominantly to the critical events of the age of diagnosis and referral, which were the outcome/dependent variables. A multiple regression procedure was chosen to answer research questions two and three, as it was the best procedure to determine relationships between variables and also predict the contribution of individual, yet multiple, independent variables on the dependent variables. Distinguishing the variables that contribute to the critical events of age of diagnosis and age of referral was a necessary step in creating service improvements related to responsiveness in the field of EI for children with BVI.

Q4 How do the results from this study compare to the results reported in the 2013 Babies Count analysis (Hatton et al., 2013), including
- a. Trends in child and service characteristics; and
- b. Differences that may be relevant for EI service providers?

Question four compared the results from the most current previous research utilizing the Babies Count database by Hatton and colleagues in 2013 and the results found in this research study. By comparing the findings from two research studies, using the same database, longitudinal trends relevant to educators, program administrators, and university preparation programs were established and uncovered. Cross tabulation analysis and t-test for significance was unable to be performed since considerable differences existed between the two samples. One issue was the difference in sample size. The sample size from Hatton et al. (2013) was 5,391 and the current sample was 588. The second issue was a significant change in the construct measurement of the independent variables, specifically the prevalence of additional disability or level of support needs, and level of functional visual ability. Therefore, a side-by-side visual comparisons was completed instead of statistical analysis. This process was similar to Hendershot and Crews' (2006) process of post-harmonization of two data sets for comparison.

The comparison between the old and new data collection form is demonstrated in Appendix B. Table 4 lists the comparisons analyzed between this study and Hatton et al., (2013).

Table 4

Comparisons Between Current and Previous Data

Hatton, et al. (2013)	Current study
Prevalent eye conditions	Prevalent eye conditions
Age at diagnosis per diagnosis	Age at diagnosis per diagnosis
Age at referral per diagnosis	Age at referral per diagnosis
Age at entry per diagnosis	Age at entry per diagnosis
Prevalence of additional disabilities	Level of support needs
Visual impairment only	Typical support needs
Development delay	Mild to moderate support needs
Additional disabilities	Severe or intensive support needs
Level of functional vision	Level of functional vision
Not legal blindness	Typical visual ability
Not legal blindness	Low vision
Legal blindness	Functions at the definition of blindness
Legal blindness	Meets the definition of blindness

Sample Size

The previous research using the Babies Count database included three different time spans or data sets. Table 5 outlines the timelines and sample sizes of previous data analysis using the Babies Count database. The first analysis was of the very first year of the project. It included 406 participants and covered the submission period of January 1998 to June 1999 for a total of 18 months (Hatton, 2001). The second analysis included 2,155 participants and covered January 2000 to December 2004, which was four years of data collection (Hatton et al., 2007). The third and most recent data analysis included the largest sample of 5,931 participants over 6 years, 4 months from January 2005 to April 2011 (Hatton et al., 2013). The current analysis consisted of a much shorter time period than the previous data analyses and covered 14 months of data collection from March 2016 to May 2017, which represented the first year of the new and revised data collection form and online submission procedures.

Table 5

Previous Data Analysis Using Babies Count Database

Dates	Timespan of study	Sample size
January 1998 to June 1999	18 months	406
January 2000 to December 2004	4 years	2,155
January 2005 to April 2011	6 years, 4 months	5,931
March 2016 to May 2017	14 months	588

As is shown in Table 5, the examination met the needed sample size to conduct all statistical procedures appropriately. G* Power 3.1 was used to determine the appropriate sample size needed for all research questions. Though a required sample size is not needed to obtain descriptive statistics, a sample size of 20 per independent variable was needed to conduct a valid multiple regression for question two and three. The sample size of 588 met the requirement for all analysis procedures.

The first grouping of data were received April 21, 2017 from the New Mexico School for the Blind and Visually Impaired (NMSBVI). This data set included only 77 entries and only represented surveys completed at the child’s time of exit from the early intervention program. This sample size was not sufficient to complete the data analysis required for the research questions. A second request for additional data to include surveys completed at the entry to programs was made to NMSBVI, which resulted in a second data set being received on June 7, 2017. This new data set included the former and had a total of 656 surveys. The cleaning process began with the removal of invalid surveys or entries that included dummy or trial attempts at data collection, duplicates, and incomplete survey entries. These incomplete survey entries appeared to be those which were started, but not finished and did not contain enough information to be included in the final sample. The final sample number was 588 and included data from five state programs.

Two statewide programs from schools for the blind represented the states of New Mexico and Utah. Also, Maryland and Washington presented by their state schools for the blind in addition to local early intervention programs throughout the state; in Maryland, five county programs contributed to the sample and in Washington, one county program as well as two non-profit agencies contributed. A non-profit program located in the northern region of the state, represented the state of California.

New Mexico contributed the most to the sample with a total of 173 entries for 29.4% of the sample. Utah was second with 136 entries for 23.1% of the sample. California was the third single program contributor with 104 entries and 17.7% of the sample. Both Washington and Maryland had multiple programs within the state contribute the overall sample. Washington included its state school plus two county programs and two non-profit agencies for a total of 105 entries for 17.9% of the sample. Maryland's contribution included its state school and also five county programs with 70 entries for 11.9% of the overall sample. Table 6 describes the breakdown of the sample according to each state representation.

Table 6

Geographical Location of the Sample by State

State and program		*n*	%
New Mexico		173	29.4
	State school for the blind (173)		
Utah		136	23.1
	State school for the blind (136)		
Washington		105	17.9
	State school for the blind (48)		
	County A (48)		
	County B (19)		
	Non-profit agency (9)		
California		104	17.7
	Non-profit agency (104)		
Maryland		70	11.9
	State school for the blind (49)		
	County A (14)		
	County B (4)		
	County C (1)		
	County D (1)		
	County E (1)		
Total sample		588	100.0

The raw data set was additionally cleaned and coded. The coding progress included not only coding written answers on the survey into numbers according to categories, but also calculating ages with the dates of events given on the survey. The data set included a variety of variables, both categorical and continuous. The categorical variables were coded in numbers according to the options of answers. The continuous variables were interval. Most of the variables were directly created from questions on the survey, however two types of additional variables were created for the purpose of data analysis for the research questions. The first calculated variable was the ages when diagnosis, referral, and enrollment occurred. The survey asked for dates, so ages of these events were calculated from the dates within the raw data set and the individual child's birthday. The second calculated variable involved questions with multiple answers. Some survey questions indicated a "check all that apply" prompt, therefore more than one response was included in the raw data set. Each of these responses was included in the coding, and an additional variable was created to indicate the number of responses for each entry. Those include additional eye conditions in the right and left eyes, additional medical and health condition, ethnic groups, developmental delayed domains, and additional early intervention services. A list of all the coding used for every variable within the data analysis is included in Appendix E.

Internal Consistency

In order to identify or interpret potential trends in the data, the issue of internal consistency was addressed. One issue regarding internal consistency was that inter-rater reliability had never been established within the database. Because 13 agencies in five states throughout the United States were represented within the sample, there may be inconsistences amongst all the professionals completing the data collection form and inputting information into the database.

Another issue related to internal consistency was that EI systems and service delivery across the United States are diverse and unstandardized. Early intervention has general guidelines set by IDEA, however the professionals completing the data collection process all work within different systems across the individual states and local communities, including public and private agencies that all provide various models of EI services. Differences in data collection procedures may have existed according to geographical locations per agency policy.

To reduce the threat of internal consistency due to many different professionals from diverse service delivery models completing the data collection form, the developers of the data collection procedures created a very detailed instructional manual. There were detailed instructions for each question of the survey embedded and easily located on the online submission website. It was outside the scope of this study to fully explore the inter-rater reliability issue.

Summary

Information related to the responsiveness of service delivery is valuable to the field of EI for children with BVI, especially as it may answer the question, “Why are infants and toddlers with BVI not getting access to services immediately?” The inquiry contributed to quality services by identifying potential key components of the ability of service delivery programs to provide needed and appropriate services within a timely manner. The identification of variables related to timely delivery of services will assist the field of EI/BVI in strategies that can be implemented to improve program delivery. Goal number one of the National Agenda highlights the critical nature of early referral within 30 days of a child’s diagnosis to “facilitate optimal learning and development” (Huebner et al., 2004), which occurs during infancy. Table 7 describes the procedures used, including the groups of independent and dependent variables, for each research question.

Table 7

Statistical Procedures and Variables for each Research Question

Research question	Source (Hatton or new)	How analyzed	Independent variable	Dependent variable
Q 1	New	Descriptive statistics	Child characteristics Family characteristics Service characteristics	
Q 1a	New	Descriptive statistics	Age of diagnosis Age of referral	
Q 2a	New	Multiple regression	Child characteristics Family characteristics Service characteristics	Age of diagnosis
Q 2b	New	Multiple regression	Child characteristics Family characteristics Service characteristics	Age of referral
Q 3	New	Multiple regression	Child characteristics Family characteristics Service characteristics	Age of diagnosis Age of referral
Q 4	New	Side by side	Prevalent eye conditions Level of support needs Level of functional vision Age at critical events	
	Hatton	Side by side	Prevalent eye conditions Prevalence of additional disabilities Level of functional vision Age at critical events	

Currently, the Babies Count database is the only database of its kind that gathers information on a local, state, and national level. This study has continued to build a longitudinal understanding of the characteristics within the population of infants and toddlers with BVI, but also analyzed key components to timely delivery of services to families to improve the overall quality of specific vision services in EI programs through the utilization of the Babies Count database.

Researcher Subjectivity Statement

At the very core of me as a researcher is the belief that data tell a story and more importantly, that research can and should be used to inform practice. Educational programs, both direct and indirect, can be continuously improved by exploring data to inform practice. My approach to this research project was not only one of researcher, but also as a teacher and program administrator to use data to inform decisions and implement best practices.

My background in early childhood special education, as well as education for children with BVI, has significantly influenced my views and opinions on how services should be provided to help facilitate and strengthen all developmental skills in young children with BVI and also to benefit families through support services to facilitate family well-being and resilience. I strongly believe in the effectiveness of appropriate early intervention services for young children with BVI, and especially early support services for families at the beginning of their journey as parents of children who experience the world without vision or with different visual and developmental abilities.

My professional perspective is grounded in a systems approach to specialized BVI/EI services, such as Bronfenbrenner’s ecological approach to social systems theory.

I feel that the transactional nature of nested systems, with the family as the microsystem and EI services as the mesosystem, is crucial to quality comprehensive support services to children and families. Also the transdisciplinary relationship-based practices within the system of early intervention is necessary to fully support and encourage children as whole people rather than provide services from multiple disciplines within silos. I value my ability to collaborate and partner with educational professionals to coach them in the unique needs and strengths of children with BVI as well as learn from others in expanding my own knowledge base.

CHAPTER IV

RESULTS

This study explored the characteristics related to a sample of the population of infants and toddlers with blindness or impairment (BVI) through a quantitative analysis of the secondary database called Babies Count. The characteristics in this analysis included those focused on the children's visual conditions, medical conditions, and developmental delays. Also, the family characteristics explored included ethnic make-up, primary language, family structure, and age and education of parents and caregivers. In addition to child and family characteristics, characteristics related to early intervention (EI) services (including specialized visual impairment supports) the child and family received were examined. Special attention was given to the ages of children at critical events such as diagnosis of visual impairment, referral to specialized visual impairment services, and enrollment or entry to specialized visual impairment services. The results not only included a descriptive analysis of the population according to these special characteristics unique to this sample, but also an inferential analysis to explore how characteristics of the child, family, and services were related to, and may explain or predict, the occurrence of these critical events. Additionally, since the Babies Count database has had previous analyses conducted (Hatton, 2001; Hatton et al., 2013; Hatton et al., 2007), the current analysis completed a comparison for a longitudinal look at the trends of this unique population of infants and toddlers with BVI.

The current study included a sample of 588 children aged birth to 36 months of age who were receiving specialized visual impairment services in five states. Those states were California, New Mexico, Utah, Maryland, and Washington. These five states were the only states to have one or more programs that provided specialized EI services to children with BVI. The respondents to the Babies Count survey, those who completed the online data collection form, were specialized vision impairment providers of EI services. The providers completed surveys for each child with BVI on their caseloads. While the respondents were EI support providers, the data explored represented individual children and therefore the participants in the study are referred to herein as the children with BVI. The results are reported from this point of view.

Research Question 1

Q1 In the last year, what are the most prevalent child, family, and service characteristics of infants and toddlers with blindness and visual impairment, including

a. What is the gap between age of diagnosis of visual impairment and age of referral to specialized vision services?

Descriptive Statistics That Describe Visual and Health Conditions and Development

The first data analysis of this study focused on the descriptive statistics for the variables within the entire sample. This procedure also answered the first research question. The categorical variables are reported as the frequency of the responses and also the percentage of the total sample of responses. The continuous variables are reported as mean, variance, standard deviation, minimum, and maximum. Overall the sample was a total of 588 children with BVI, however not all variables represented the total sample. In order to respect families' privacy and willingness to share some pieces of information, all questions on the survey included an option of unknown or declined to answer. This option on each question on the data collection form resulted in missing data and created a differential of sample sizes for each question. For this reason, the sample size is reported for each variable. Appendix F includes a full report of all the descriptive statistics for each variable, both continuous and categorical.

Boys represented more than 50% of the sample (*n* = 308, 52.4%), with girls just under 50% (*n* = 280, 47.6%). Just over half of the children were born at full term (*n* = 332, 59.5%) with the remaining born prematurely (*n* = 256, 40.5%). About 23% (*n* = 129) were born 3 to 7 weeks earlier than the typical 38 to 40 weeks gestational age, and the remaining 16.5% (*n* = 97) were born even earlier. There were 30 children with unknown gestational age at birth to the respondent. The majority of the sample (*n* = 557, 94.7%) were single births, and the remaining (*n* = 31, 5.3%) were members of a multiple birth, as the child was either a twin or triplet. There was great variability within the weight of children at birth with an average weight at birth of 5.98 pounds (*SD* = 2.2). The smallest baby was born weighing 1.1 pounds and the largest or heaviest baby was 15 pounds. However, 15% (*n* = 89) of the overall sample did not report the weight of the child at birth. Table 8 describes the frequency and percentage of the characteristics related to children’s birth history, including gender, gestational age, multiple birth, and weight.

Table 8

Birth History (n = 588)

Child characteristic- categorical	*n*	%
Gender		
Male	308	52.4
Female	280	47.6
Total	588	100.0
Gestational age at birth		
Full term	332	56.5
37-33 weeks gestation	129	21.9
Less than 28 weeks gestation	53	9.0
32-28 weeks gestation	44	7.5
Total	558	100.0
Unknown/missing/unreported	30	
Multiple birth		
Single birth	557	94.7
Twin birth	30	5.1
Triplet birth	1	0.2
Total	588	100.0

Child characteristic- continuous	*n*	*lbs.*
Birth weight (in pounds)		
Mean		5.98
Variance		5.0
Standard deviation		2.2
Minimum		1.1
Maximum		15.2
Sample	499	
Unknown/missing/unreported	89	

Twenty-five (25) eye conditions were reported for both the left and right eyes. For ease of data analysis, the eye conditions were grouped into eight categories. These categories were cortical visual impairment (CVI) (including delayed visual maturation

(DVM)), optic nerve hypoplasia (ONH), retinopathy of prematurity (ROP), albinism, structural, retinal, other/miscellaneous eye conditions, and eye conditions reported as unknown. The categories of structural, retinal, and other/miscellaneous includes more than one eye condition. The structural category included conditions related to abnormal or atypical formations of structures of the eye: aniridia, microphthalmia or anophthalmia, coloboma, corneal defects such as Peter's anomaly, and Goldenhar syndrome. The retinal category included conditions that primarily affect the retina in the eye, including Leber's congenital amaurosis (LCA), retinoblastoma, familial exudative vitreous retinopathy (FEVR), and other retinal defects or disorders. Even though ROP is also considered a retinal disorder, it was separated into its own category. The miscellaneous eye condition category contained a variety of miscellaneous eye conditions including nystagmus, strabismus, cataracts, glaucoma, ocular motor apraxia (OMA), optic atrophy, persistent hyperplastic primary vitreous (PHPV), hemianopia, nerve palsy or ptosis, choroidal hemangioma, aniscoria, and high refraction.

The most prevalent eye condition that led to uncorrectable visual impairment was CVI, at 29.1% of the total sample (*n* = 171). The second most prevalent eye condition was ONH with 10.9% of the overall sample (*n* = 64). The third most prevalent eye condition was ROP at 8.5% of the sample (*n* = 50). Structural conditions accounted for 6.5% (*n* = 38) of the sample's retinal conditions, 4.1% (*n* = 24); and albinism, 3.1% (*n* = 18). The miscellaneous eye condition category accounted for 22.4% (*n* = 132). Additionally, 91 children did not have a diagnosed visual condition, representing 15.5% of the sample. Table 9 describes the frequency and percentage of the most prevalent primary eye conditions.

Table 9

Primary Vision Diagnosis in Both Eyes

Eye condition	*n*	%
CVI/DVM	171	29.1
ONH	64	10.9
ROP	50	8.5
Structural	38	6.5
Retinal	24	4.1
Albinism	18	3.1
Miscellaneous	132	22.4
Unknown diagnosis	91	15.5
Total	588	100.0

Note: Cortical Visual Impairment or Delayed Visual Impairment (CVI/DVM), Optic Nerve Hypoplasia (ONH), Retinopathy of Prematurity (ROP)

The primary eye conditions in the right and left eye were reported separately on the data collection form. A few children may have had a different eye condition in each eye or may have had no eye condition in one eye. The primary eye condition causing the uncorrectable visual impairment was reported as the primary eye condition for both eyes. Appendix F highlights the individual eye conditions, both primary and secondary, for the right eye and the left eye.

In addition to the children's primary eye conditions, over half of all children in the sample had a secondary, or additional, eye condition, and sometimes more than one. In the right eye, 51.4% ($n = 302$) of the children in the sample were reported as not having a secondary eye condition and 54.6% ($n = 321$) of the children in the sample had no secondary eye condition in the left eye.

Since the variable related to secondary eye condition could have had multiple responses for each child, the overall number of responses was larger than the overall sample of 588. In the right eye, the sample included 688 reported eye conditions; in the left eye, the sample included 672 reported eye conditions. These results indicated many children had more than one reported condition, though approximately 50% only had one. In the right eye, 218 children were reported to have only one secondary eye condition (37.1%); in the left eye, 205 were reported (34.9%) to have one secondary eye condition. The prevalence of 2 or more secondary eye conditions was much less; 10% in the right eye (*n* = 68) and 11.5% in the left eye (*n* = 62).

In the right eye, the three most prevalent secondary eye conditions were refractive error (*n* = 88, 15.0%), nystagmus (*n* = 87, 14.8%), and strabismus (*n* = 78, 13.3%). In the left eye, the three most prevalent were also nystagmus (*n* = 86, 14.6%), refractive error (*n* = 80, 13.6%) and strabismus (*n* = 72, 12.2%). CVI was also reported as a secondary eye condition (*n* = 23, 3.9%) in both the right and left eyes. When the secondary condition of CVI was combined with the reported primary incidence, it increased the overall incidence of CVI to over one-third of the overall sample (*n* = 194, 33%).

In the right eye, amblyopia (*n* = 37, 6.3%), optic atrophy (*n* = 22, 3.7%), ptosis (*n* =14, 2.4%), cataract (*n* = 8, 1.4%), and coloboma (*n* = 7, 1.2%) were also prevalent secondary eye conditions. Miscellaneous right eye secondary vision conditions included glaucoma, ocular motor apraxia, microphthalmia, PHPV, hemianopia, ROP, retinal disorder, corneal disorder, and vitreous hemorrhage. These conditions together comprised 3.7% (*n* = 22) of the sample.

In the left eye, optic atrophy (*n* = 20, 3.4%), amblyopia (*n* = 20, 3.4%), ptosis (*n* = 15, 2.6%), cataract (*n* = 9, 1.5%), and coloboma (*n* = 5, 0.9%) were also prevalent secondary eye conditions. Miscellaneous left eye secondary vision conditions also included glaucoma, microphthalmia, hemianopia, OMA, ROP, PHPV, retinal disorder, and vitreous hemorrhage. These conditions together comprised 3.6% (*n* = 21) of the sample. Table 10 describes the frequency and percentages of each secondary eye condition and Table 11 describes the number of secondary eye conditions present in each child within the overall sample.

Table 10

Secondary or Additional Visual Conditions (n = 588)

Visual Condition	Right eye		Visual Condition	Left eye	
	n	%		*n*	%
None	302	51.4	None	321	54.6
Refractive error	88	15.0	Nystagmus	86	14.6
Nystagmus	87	14.8	Refractive error	80	13.6
Strabismus	78	13.3	Strabismus	72	12.2
Amblyopia	37	6.3	CVI/DVM	23	3.9
CVI/DVM	23	3.9	Optic atrophy	20	3.4
Optic atrophy	22	3.7	Amblyopia	20	3.4
Ptosis	14	2.4	Ptosis	15	2.6
Cataract	8	1.4	Cataract	9	1.5
Coloboma	7	1.2	Coloboma	5	0.9
Miscellaneous	22	3.7	Miscellaneous	21	3.6
Total	688		Total	673	

Note: Cortical Visual Impairment or Delayed Visual Impairment (CVI/DVM)

Table 11

Number of secondary or additional eye conditions

Right eye	*n*	%	Left eye	*n*	%
None	302	51.4	None	321	47.7
1 additional	218	37.1	1 additional	205	34.9
2 additional	47	7.0	2 additional	45	7.6
3 or more	21	3.0	3 or more	17	3.9
Total	588	100.0	Total	588	100.0

Other variables are included in this analysis that further describe a child's visual impairment, specifically the etiology of the primary eye condition and level of functional visual ability. Etiology describes when the visually disabling condition occurred, either prior to birth (prenatal), during or right after birth (perinatal), or sometime after birth or during early months or years in childhood. Over 50 percent of the sample (*n* = 232, 53.7%) was reported to have the primary visual condition occur during the prenatal period, 20% (*n* = 87, 20.1%) occurred during the perinatal period, and approximately a quarter (*n* = 113, 26.2%) occurred postnatally. Over a quarter of the children in the sample (*n* = 156, 26.5%) had an etiology that was unknown or was not reported by the respondent. One measure of the etiology of the primary visual impairment condition was if the condition were caused by a non-accidental trauma, such as Shaken Baby Syndrome. While the majority of the sample (*n* = 555, 95.5%) reported the etiology was not caused by non-accidental trauma, a small portion of children (*n* = 26, 4.5%) sustained a non-accidental trauma to cause their visual impairment.

Additionally, almost 30% of the overall sample (*n* = 176, 29.9%) were prescribed glasses or contact lenses to assist with correcting a refractive error that affected visual acuity, though the level of correction is unknown. However, the majority (*n* = 408, 69.4%) required no visual optical devices, and a very small percentage (*n* = 4, 0.7%) had one or more prosthetic eyes. Table 12 describes the descriptive statistics for the etiology of visual condition and the use of visual optics.

Table 12

Etiology and Use of Optics (n = 588)

Child characteristic	*n*	%
Etiology of vision diagnosis		
Prenatal	232	53.7
Postnatal	113	26.2
Perinatal	87	20.1
Total	432	100.0
Unknown/missing/unreported	156	
VI due to non-accidental trauma		
Not due to non-accidental trauma	555	95.5
Due to non-accidental trauma	26	4.5
Total	581	100.0
Unknown/missing/unreported	7	
Use of visual optics		
No visual optics needed	408	69.4
Glasses only	170	28.9
Prosthetic eye(s)	4	0.7
Both glasses and contacts	3	0.5
Contacts only	3	0.5
Total	588	100.0

Regarding the level of functional visual ability, 41% (*n* = 241) of the sample was reported to have low vision, while approximately 35% (*n* = 205, 34.9%) of the children had their vision described as either meets or functions at the definition of blindness. Slightly less than a quarter of the sample (*n* = 142, 24.1%) had vision that was reported as typical or near normal visual functioning.

The primary learning channel was reported as a choice of visual, auditory, or tactual. Over 50% (*n*= 274, 57.7%) of the sample was reported to be primarily visual learners, and the learning channel of auditory was second in prevalence at 30.3% (*n* = 144). A tactual means of learning was the least reported learning channel at 12.0% of the sample (*n* = 57). Also, a total of 113 children were reported as having a learning channel that was unknown to the respondent, which indicated that the primary learning channel of almost one-fifth of the total sample of children could not be determined. Table 13 describes the variables related to the characteristics of functional visual ability and primary learning channel of the sample.

Table 13

Functional Visual Ability and Primary Learning Channel (n = 588)

Child characteristic	*n*	%
Level of functional vision		
Low vision	241	41.0
Typical or near normal vision	142	24.0
Functions at the definition of blindness (FDB)	127	22.0
Meets the definition of blindness (MDB)	78	13.0
Total	588	100.0
Primary learning channel		
Visual	274	46.6
Auditory	144	24.5
Tactual	57	9.7
Total	475	100.0
Unknown/missing/unreported	113	

In addition to children's visual impairment, the Babies Count database included information on additional characteristics of children with visual impairment, such as other medical/health conditions and developmental delays. The children in this sample were found to have a great range of additional medical and health conditions concurrent to their visual conditions. The number of medical/health conditions totaled more than the sample, as many children had more than one, and the sample size for this variable was 1088. The medical/health conditions were also grouped into seven categories, since more than 25 individual medical conditions were identified. These categories were endocrine disorders, Deaf/hard of hearing, feeding problems, neurological conditions, global syndromes, and miscellaneous, which includes many less prevalent medical conditions. The neurological category included cerebral palsy, seizures, autism spectrum disorder (ASD), spina bifida, and both congenital and acquired brain abnormalities. The global syndrome category included chromosomal, mitochondrial, metabolic, genetic, and hereditary disorders, as well as cranio-facial disorders. The miscellaneous category included a variety of additional medical conditions such as cancer, heart conditions, gastro-intestinal/reflux issues, respiratory problems, sleep issues, allergies, born with addiction, and medical technology dependence.

While 31.5% (*n* = 185) were reported to have no additional medical/health condition, the most prevalent medical/health conditions were neurological (*n* = 234, 39.8%), and feeding problems (*n* = 195, 32.8%). An endocrine disorder accounted for 6.5% (*n* = 38), and 7.3% (*n* = 43) of the children had varying degrees of deafness or were hard of hearing. Children with global syndromes, such as a chromosomal disorder, represented 9.7% of the sample (*n* = 57). Additionally, 39.8% of the sample was reported to have medical/health conditions in the miscellaneous category (*n* = 181), which included a variety of diverse medical conditions of lower incidence.

Since many children were reported as having more than one additional medical or health condition concurrent with their visual condition, the possibility of more than one response per child existed. While 31.5% of the children were reported as having no other medical conditions (*n* = 185), 44% of the children were reported to have one (*n* = 160) or two (*n* = 101) medical conditions, and 24% were reported to have three (*n* = 69) and four or more (*n* = 73) medical conditions. Table 14 describes the additional medical and health conditions reported in the sample total of 1088, including the number of conditions per child.

Table 14

Medical/Health Conditions (n = 588)

Child characteristic	*n*	%
Medical condition		
Neurological	338	57.5
Miscellaneous	234	39.8
Feeding problems	193	32.8
None	185	31.5
Global syndrome	57	9.7
Deaf/hard of hearing	43	7.3
Endocrine	38	6.5
Total	1088	
Number of medical conditions		
None	184	31.5
One condition	160	27.2
Two conditions	101	17.2
Three conditions	69	11.7
Four or more conditions	73	12.4
Total	588	100.0

Regarding the incidence of developmental delays within the sample, almost 14% (*n* = 82, 13.9%) of the sample of children was reported to have no developmental domains delayed or additional disabilities beyond their BVI. However, about 40% (*n* = 232, 39.5%) of the children were reported to be delayed in all six developmental domains. Regarding the continuum from one domain to five domains, 8.9% (*n* = 52) had one domain delayed, 10.5% (*n* = 62) had two, 8.7% (*n* = 51) had three, 7.6% (*n* = 45) had four, and 10.9% (*n* = 64) had five developmental domains delayed.

The developmental domains included the areas of cognition, language, social, adaptive, and both fine and gross motor. Within the overall sample of 588 children, there were 2309 responses as the majority of children had two or more developmental domains delayed. Motor delays were indicated as the domain most likely to be delayed in this sample, with 438 children reported to have gross motor delays (75%), and 414 children reported with fine motor delays (70.4%). Language delays were the next most prevalent and occurred in 399 children (67.9%). Cognition was close behind at 62.9% and occurred in 368 children. The two domains least likely to be delayed were adaptive and social, with 302 (51.4%) children with social delays and 306 children with adaptive delays (52.0%).

While children were reported to have delays in all six domains, the level of delay or severity of individual delays within each domain was not indicated or asked within the data collection tool. Overall developmental support needs were reported as a separate variable. Only 13.8% of the sample (n = 81) were reported to have typical support needs for a child of similar age, however the majority of the children in the sample (*n* = 507, 86.2%) was reported to have more support needs than children without disabilities. Half of the entire sample (n = 294, 50.0%) had mild to moderate support needs and 36.2% (n = 213) of the children were reported to have intensive support needs. Table 15 describes the frequency and percentage of developmental domains delayed, the types of domains, and the level of developmental needs within the sample.

Table 15

Developmental Delays (n = 588)

Child characteristic	*n*	%
Developmental delays		
Gross motor	438	75.0
Fine motor	414	70.4
Language	399	67.9
Cognitive	368	62.6
Adaptive	306	52.0
Social	302	51.4
None	82	13.9
Total	2309	
Number of domains delayed		
All six domains delayed	232	39.5
None	82	13.9
Five domains delayed	64	10.9
Two domains delayed	62	10.5
One domain delayed	52	8.9
Three domains delayed	51	8.7
Four domains delayed	45	7.6
Total	588	100.0
Level of developmental need		
Mild/moderate support needs	294	50.0
Intensive support needs	213	36.2
Typical support needs	81	13.8
Total	588	100.0

Summary of Child Characteristics

The sample presented in the analysis totaled 588 children with an equal representation of boys and girls. The majority were born full term, with almost half premature, and 15% of the children were born more than two months early. The three most prevalent eye conditions were CVI, OHN, and ROP. CVI was the most prevalent and over 1/3 of the entire sample were reported to have CVI either as a primary or secondary eye condition to cause their uncorrectable visual impairment. Another notable trend was over half of the children had a neurological medical condition. These results about CVI and additional neurological compromises indicate a large presence of neurological visual impairments within this sample of young children with BVI.

In addition to a large presence of neurological visual impairment, the results indicated a large percentage of the sample had additional disabilities, with over a third of the children with intensive or profound developmental needs and delays in all six developmental domains. One third of the children had feeding problems. However, another third of the children were reported to have no additional medical needs, but only a little over 10% did not have additional developmental needs. Also, only about a third of the children had very limited vision with the majority of children with low vision or vision within normal limits for their age.

Descriptive Statistics That Describe the Family and Caregivers

The ethnicity of the children within the Babies Count database was characterized by many children being included in more than one ethnic group. On the Babies Count data collection form, respondents were able to choose more than one option for ethnicity of the child. The majority of the children in the sample (*n* = 512, 87%) had only one ethnic group reported and 11% of the sample (*n* = 65, 11.1%) were reported to have two or more. Only 11 children were reported to have an ethnic makeup unknown to the survey respondent. Children of Caucasian decent, both full or partial, comprised 48.7% (*n* = 325) of the sample. Hispanic or Latino decent, both full and partial, comprised 27.1% (*n* = 181) of the sample. The other ethnic groups comprised less than 10% each, with African Americans or Black at 7.3% (*n* = 49), Native American at 6.7% (*n* = 45), Asian at 4.8% (*n* = 32), and Pacific Islander at 2.8% (*n* = 19). Children with Middle Eastern descent comprised the smallest proportion of the sample with less than 1% (*n* = 5, 0.7%).

The primary language of families and children was reported as either English or not English, without specification of the actual language spoken by the family. English was reported as the primary language at a little over 80% (*n* = 478, 81.6%) and not English at less than 20% (*n* = 108, 18.4%). Two children and families had a primary language unknown to the respondent. Table 16 describes the ethnic makeup of the sample including primary language of the family.

Table 16

Family's Ethnicity and Language (n = 588)

Family characteristic	*n*	%
Ethnicity		
Caucasian/White	325	48.7
Hispanic/Latino	181	27.1
African American/Black	49	7.3
Native American	45	6.7
Asian	32	4.8
Pacific Islander	19	2.8
Unknown	11	1.6
Middle Eastern	5	0.7
Total	667	
Number of ethnic groups		
One group	512	88.7
Two or more groups	65	11.3
Total	577	100.0
Ethnic group unknown	11	
Language		
English is primary language	478	81.6
English is not primary language	108	18.4
Total	586	100.0
Primary language is unknown	2	

Additional questions on the data collection form revealed more specific information about the individual family structures, including with whom the child lived or who was identified as the primary caregivers, and also the number of siblings of the children in the sample. The majority of children in the sample lived with and are being reared by their biological parents. A two-parent household was the caregiver of 435 children (74.1%), and single parents were the caregivers of 105 children (17.9%). Six percent of the sample (*n* = 35) was reported to live with a foster or adoptive family. Other family structures comprised of related or unrelated adults represented 2% of the sample (*n* = 12). Only one child had a family structure that was unknown to the respondent. A large percentage of the children did not have any siblings (*n* = 316, 53.7%). However, 23.3% (*n* = 137) had only one sibling. Less than 25% of the sample had more siblings, as 78 children had 2 siblings (13.3%) and 57 children lived in a larger family with 3 or more siblings (9.7%). Table 17 describes the various family structures and number of siblings present in the family of the children in the sample.

Table 17

Family Structure (n = 588)

Family characteristic	*n*	%
Child's caregivers (child lives with)		
Biological/step parents	435	74.1
Single biological parent	105	17.9
Adoptive/foster family	35	6.0
Non-parent adult(s)	12	2.0
Total	587	100.0
Unknown/missing/unreported	1	
Presence of siblings		
Child has no siblings	316	53.7
Child has one sibling	137	23.3
Child has two siblings	78	13.3
Child has three or more siblings	57	9.7
Total	588	100.0

A large percentage of the ages of both the mother (*n*= 185, 31.5%) and father (*n* = 239, 40.7%) was not reported within the sample and was therefore unknown. However, for 403 children, the youngest mother was 15 years old and the oldest was 46 (*M* = 28.3, *SD* = 6.3). For 349 children, the youngest father was 16 years old and the oldest was 56 (*M* = 31.2, *SD* = 6.9). Table 18 describes the ages of mothers and fathers of the reported sample.

Table 18

Age of the Child's Biological Parents at Birth

Parents' age	Years
Mother's age at birth (n = 403)	
Mean	28.3
Standard deviation	6.3
Minimum	15
Maximum	46
Father's age at birth (n = 349)	
Mean	31.2
Standard deviation	6.9
Minimum	16
Maximum	56

When grouped by decade of years of age, mothers of children between 20 and 29 years were the largest group (*n* = 198, 33.7%) and mothers in their thirties were the second largest group (*n* = 144, 35.7%). Mothers of children between the ages of 40 and 46 were the smallest proportion (*n* = 23, 5.7%). Teen mothers of children with BVI comprised almost 10% (*n* = 38, 9.4%) of the sample.

For fathers of children, the largest group was men between 30 and 39 years old (*n* = 157, 26.7%) and also between 20 to 29 years old (*n* = 140, 40.1%). The two smallest groups were the oldest group, between 50 and 56 years (*n* = 2, 0.6%) and the youngest group, between 16 to 19 years (*n* =12, 3.4%). These results for ages of the mothers and fathers of children with BVI reveal that the majority were between the ages of 20 and 49, with a small percentage as very young, teen parents. Table 19 describes the ages of mothers and fathers grouped according to age range.

Table 19

Age of the Child's Parents at Birth, by Age Groups (n =588)

Parents' age	*n*	%
Mother's age at birth (n = 403)		
20-29 years old	198	49.2
30-39 years old	144	35.7
15-19 years old	38	9.4
40-46 years old	23	5.7
Total	403	100.0
Unknown/missing/unreported	185	
Father's age at birth (n = 349)		
30-39 years old	157	45.0
20-29 years old	140	40.1
40-49 years old	38	10.9
16-19 years old	12	3.4
50-56 years old	2	0.6
Total	349	100.0
Unknown/missing/unreported	239	

The educational level of mothers and fathers of the children in the sample were also largely unreported in the database, with the educational level of 145 mothers and 199 fathers unknown. The education level of an associate of arts (AA) degree or some college were the largest percentage of the reported sample for both mothers (*n* = 151, 34.1%) and fathers (*n* = 116, 29.8%). The second highest percentage of the sample was a high school diploma degree for again both mothers (*n* = 122. 27.5%) and fathers (*n* = 114, 29.3%). A college degree, including a graduate degree, formed the smallest percentage of parents' education, as 20.1% (*n* = 89) of mothers had an undergraduate degree and 11.1% (*n* = 49) had a graduate degree; 20.6% (*n* = 80) of fathers had an undergraduate degree and 10.8% (*n* = 42) had a graduate degree. A small percentage of mothers (*n* = 32, 7.2%) and fathers (*n* = 37, 9.5%) had not graduated from high school. Table 20 describes the level of education of the children's caregivers.

Table 20

Education of the Child's Caregivers (n = 588)

Caregivers' education	*n*	%
Mother (*n* = 443)		
Associate degree/some college	151	34.1
High school diploma	122	27.5
Undergraduate degree	89	20.1
Graduate degree	49	11.1
Did not graduate from high school	32	5.4
Total	443	100.0
Unknown/missing/unreported	145	
Father (*n* = 389)		
Associates degree/some college	116	29.8
High school diploma	114	29.3
Undergraduate degree	80	20.6
Graduate degree	42	10.8
Did not graduate from high school	37	9.5
Total	389	100.0
Unknown/missing/unreported	199	

Summary of Family Characteristics

The results found that the families of the children are very diverse, yet some notable similarities were discovered. While all ethnic groups were represented in the sample, over half were Caucasian or White and over a quarter were Hispanic or Latino. Also, over 75% of the families spoke English with the remaining quarter reported as non-English speakers. Another notable similarity in the family characteristic results indicated that about 2/3 of the parents were college educated, either some college experience or an actual degree. The majority (over 90%) of the children live with their biological parents and over half of the children were an only child. Only another quarter of the children had only one sibling. This indicated that the majority of children were in families who were small with only one or two children.

Descriptive Statistics That Describe Early Intervention Services

The children in the sample were referred for specialized visual impairment services from a variety of sources, however the majority of the referrals came from an early intervention (EI) program (*n* = 457, 78.1%). Less than 20% of the referrals came directly from a medical provider such as ophthalmologist, neurologist, or pediatrician (*n* = 98, 16.8%). Sometimes the family of the child, including parents or other related person, directly referred the child to specialized vision services (*n* = 30, 5.1%). There were 3 children in the sample with an unknown referral source reported by the provider or respondent who completed the data collection form.

The professionals who provide the specialized visual impairment services in EI were from two basic groups. The first category was a certified provider and someone who received formal university training in education of the learner with BVI. Those providers are a teacher of students with visual impairment, an orientation and mobility specialist, a deaf-blind specialist, or a vision rehabilitation specialist. Some of the respondents reported on the data collection survey that one or more of these specially trained specialists provided services to the child. For the purpose and ease of data reporting, those professionals were grouped together. Formally university trained and certified vision professionals provided specialized visual impairment services to the majority of the children in the sample (*n* = 379, 64.5%).

The second category was a professional who was employed and trained, possibly informally, by a specialized agency for children with BVI, but held no formal certification. Uncertified, but highly trained, professionals provided specialized visual impairment services to 209 children (35.5%).

As for frequency of service provision, the majority of specialized visual impairment services were provided on a once-a-month basis (*n* = 243, 41.3%) and bi-weekly or twice-a-month basis (*n* = 209, 35.5%). Only 15.5% of the children received specialized visual impairment services on a weekly basis (*n* = 91). The remaining received services on a less frequent basis, such as every other month, quarterly, annually, one time consultation, or others (*n* = 45, 7.7%).

Additionally, the majority of specialized visual impairment services were provided in the home of the child (*n* = 569, 96.8%). A very few number of children were supported in other types of environments. These include a specialized center for children with BVI (*n* = 9, 1.5%), an IDEA-described “natural environment” such as a day care setting (*n* = 4, 0.7%), an early intervention/early childhood center for all children with a range of disabilities (*n* = 4, 0.7%), or a residential care facility for children with complex medical needs (*n* = 2, 0.3%). Table 21 describes the specialized visual impairment services reported by respondents, including referral source, type of provider, frequency, and location of services.

Table 21

Child's Specialized Visual Impairment Service (n = 588)

Service characteristic	*n*	%
Referral source		
Early intervention program/Child Find	457	78.1
Medical professional	98	16.8
Family	30	5.1
Total	585	100.0
Unknown/missing/unreported	3	
Specialized vision impairment service provider		
State/national certified professional	379	64.5
Non-certified professional trained by program/agency	209	35.5
Total	588	100.0
Frequency of specialized visual impairment service		
Monthly	243	41.3
Bi-weekly	209	35.5
Weekly	91	15.5
Other (bi-monthly/quarterly/annual/consultation as needed)	45	7.7
Total	588	100.0
Location of specialized visual impairment service		
Home	569	96.8
Specialized center for children with BVI	9	1.5
Natural environment	4	0.7
Early intervention/early childhood center	4	0.7
Residential care facility	2	0.3
Total	588	100.0

Note: Blindness or visual impairment (BVI)

Children with BVI often received other EI services in addition to specialized visual impairment services, however a small percentage of children only received specialized visual impairment services (*n* = 42, 7.1%). Those that did receive other services often received more than one service. Only one EI service was provided to 124

(21.1%) children, two services were provided to 165 (28.1%) children, three services to 135 (23.0%) children, and 4 or more services to 122 (20.7%) children.

The types of EI services spanned the range of IDEA services available for children in the Part C program. The most frequently provided services were physical therapy (*n* = 361, 61.4%), occupational therapy (*n* = 354, 60.2%), special instruction (*n* = 344, 58.5%), and speech and language services (*n* = 194, 33.0%). Specialized services for the Deaf/hard of hearing (DHH) were provided to 23 children (3.9%). The remaining miscellaneous services (*n* = 97) were reported as less frequent and together comprised 16.6% of the sample, including social work, nursing, feeding or nutrition, psychological, applied behavior analysis, assistive technology, and other non-IDEA services (such as hippo-therapy, water therapy, or music therapy). These percentages do not add to 100%, as the majority (71.8%) of the children received two or more EI services. Table 22 describes the number and types of additional EI services provided to children in the sample who are BVI.

Table 22

Additional Early Intervention Services (n = 588)

Service characteristic	*n*	%
Types of early intervention services		
Physical therapy	361	61.4
Occupational therapy	354	60.2
Special instruction	344	58.5
Speech/language services	194	33.0
Miscellaneous early intervention service	97	16.6
None	42	7.1
Specialized Deaf/hard of hearing services	23	3.9
Total	1415	
Number of early intervention services		
Two services	165	28.1
Three services	135	23.0
One service	124	21.1
Four or more services	122	20.7
None	42	7.1
Total	588	100.0

Summary of Service Characteristics

The children in the analysis were reported to receive a variety of EI services, in addition to their specialized visual impairment services. While less than 10% of the sample only received EI supports from a specialized visual impairment service provider, the majority of children received at least one to three other EI services. About 20% of the children had a large EI team of over 4 or more service providers. Those services were most often a motor therapist, such as physical or occupational therapist, or an early childhood special educator for special instruction. The number of services provided to the children in the sample align with the prevalence of additional disabilities and the high level of support needs present in the sample.

The specialized visual impairment services were provided by state certified and university-trained teachers of students with BVI, but about a third of the providers were trained and employed by a special EI program for children with BVI. Services were primarily provided once or twice a month, with less than 20% of the families supported weekly. Also, the majority, over 75%, of children in the sample were referred to specialized visual impairment services from an EI Program and less than a quarter from a medical provider. This may indicate that children are already in the EI program prior to receiving specialized visual impairment services.

Descriptive Statistics That Describe Age of Diagnosis, Referral, and Enrollment

For infants and toddlers with BVI, there are three critical ages regarding responsive EI services. The first is the age at which the child was first diagnosed with a visual condition that may lead to uncorrectable visual impairment, referred to herein as the age of diagnosis. The next is the age at which the child was referred for specialized visual impairment services as a part of the individual EI service plan, known as the age of referral. And finally, the age at which the child actually began to receive those services, known as the age at enrollment.

The mean age of diagnosis of a visual condition that may lead to an uncorrectable visual impairment was 7.2 months (*n* = 502, *SD* = 6.5). The youngest a child was diagnosed at birth, or at the age of 0 months, and the oldest was 36 months, which is also the time a child actually leaves EI services. There were 85 (14.5%) children who did not have an actual diagnosis or had not yet been diagnosed with a visual condition to explain their functional visual impairment and need for specialized visual impairment services. One child had missing data for the date of diagnosis.

The mean age at which a child was referred for specialized vision services was 9.5 months (*n* = 586, *SD* = 7.1) months. The youngest child referred was 0.2 months of age, which is about one week old, and the oldest was 33.2 months old.

The mean age at which a child was enrolled in a program and began to receive specialized visual impairment services was 10.4 months (*n* = 586, *SD* = 7.2). The youngest a child received services was 0.2 months, about one week of age, and the oldest was 33.4 months. Table 23 describes the statistics related to the critical stages of access to specialized vision services.

The time gap between age of diagnosis and age of referral was calculated with the dates given in the database. However, because some children were given a diagnosis after referral to specialized visual impairment services (*n* = 152, 25.8%) and a number of children did not yet have a diagnosis (*n* = 85, 14.5%), the calculation of the time gap between age of diagnosis and age of referral is based on 348 children. The mean number of months between diagnosis and referral was 5.2 months (*SD* = 5.8). The shortest time span was also 0 months (at birth) and the longest was 26.1 months. About 75% (*n* = 442, 75.2%) of the children received their specialized visual impairment services within 30 days of their referral and the remaining 25% (*n* = 143, 24.3%) waited longer than 30 days. Table 24 describes the time between diagnosis and referral (in months) and between referral and enrollment (in days).

Table 23

Age of Diagnosis, Referral, and Enrollment (n = 588)

Service characteristic	*Months*	*n*	%
Age of diagnosis			
Mean	7.2		
Standard deviation	6.5		
Minimum	0.0		
Maximum	36.0		
Sample size		502	85.4
No diagnosis		85	14.5
Unknown/missing/unreported		1	0.1
Total		588	100.0
Age of referral			
Mean	9.5		
Standard deviation	7.1		
Minimum	0.2		
Maximum	33.2		
Sample size		586	99.7
Unknown/missing/unreported		2	0.3
Total		588	100.0
Age at enrollment			
Mean	10.4		
Standard deviation	7.2		
Minimum	0.2		
Maximum	33.4		
Sample size		586	99.7
Unknown/missing/unreported		2	0.3
Total		588	100.0

Table 24

Time between critical events

Service characteristic	*Months*	
Months between visual diagnosis and referral		
Mean	5.2	
Standard deviation	5.8	
Minimum	0.0	
Maximum	26.1	
	n	*%*
Sample	348	59.2
No diagnosis	85	14.5
Diagnosis after referral	152	25.8
Unknown/missing/unreported	3	0.5
Total	588	100.0
Days between referral and enrollment (*n* = 588)	n	%
Less than 30 days	442	75.2
More than 30 days	143	24.3
Unknown/missing/unreported	3	0.5
Total	588	100.0

Summary of Critical Events

The analysis found that for 502 children who actually had a diagnosis of a visual condition, the average age of receiving the diagnosis was 7.2 months old. The average age of referral to specialized visual impairment services was 9.5 months old. There was also great variability within the age span, as many children were diagnosed and referred at birth and some waited until they were nearing the age of leaving early intervention services. Also, the analysis found that more than 25% of the total sample actually received their visual impairment diagnosis after they were already receiving specialized visual impairment services. Regardless, for children in the study who had a diagnosis at the time of their referral, there was an average 5.2-month gap between the time they were diagnosed and the time they were referred for services. This study found that specialized visual impairment services were not being provided within 30 days of a child's diagnosis for a large majority of children as recommended by the National Agenda (Huebner et al., 2004), however once they were referred, services were provided within a timely manner.

Research Question 2

> Q2 What is the relationship among child characteristics, family characteristics, and service characteristics and
> a. age of diagnosis of blindness or visual impairment; and
> b. age of referral to specialized vision services?

Relationship Within Independent Variable Categories and Age of Diagnosis

To determine the possible relationship between the characteristics groups (child, family, and service) and age of diagnosis, an analysis of variance (ANOVA) was conducted as part of a linear multiple regression procedure. For the grouping of child characteristics, primary eye condition, $F(7, 494) = 8.140$, $p = .000$, etiology of vision condition, $F(3, 498) = 14.392$, $p = .000$, and additional medical condition, $F(7, 494) = 3.069$, $p = .000$, were the only variable groups to demonstrate statistically significant differences, or variance, to suggest a relationship to the age of diagnosis. For the grouping of family characteristics, the primary caregiver variable group, $F(7, 494) = 5.047$, $p = .001$, was the only variable group to demonstrate a statistically significant difference and a relationship to the age of diagnosis. For the grouping of service characteristics, the variable groups of state or geographical location, $F(4, 497) = 5.340$, $p = .000$, number of early intervention services, $F(4, 497) = 5.942$, $p = .001$, and type of early intervention service, *F*(7, 494) = 5.859, *p* = .000, demonstrated statistically significant differences and relationships to the age of diagnosis.

The results indicate that out of 17 independent variable groups, only seven variable groups were found to demonstrate a statistically significant difference, or variances, related to age of diagnosis. These results also suggest a correlation and are investigated in the next research question to determine the contribution of the explanatory relationship between these independent variables and the dependent variable of age of diagnosis. Table 25 highlights the results for those variable groups demonstrating significance with age of diagnosis.

Table 25

ANOVA Results for Variable Groups with Relationship to Age of Diagnosis

Variable group	*df*	*F*	*p-value*
Child characteristics			
Primary eye condition	7, 494	8.140	.000
Etiology of eye condition	3, 498	14.392	.000
Medical condition	7, 494	3.069	.004
Family characteristics			
Primary caregiver	7, 494	5.047	.001
Service characteristics			
State	4, 497	5.340	.000
Number of EI services	4, 497	5.942	.000
Type of EI service	7, 494	5.859	.000

Correlations of Independent Variables to Age of Diagnosis

Only four individual variables within the seven independent variable groups had a correlational relationship to the dependent variable of age of diagnosis, demonstrated as a Pearson correlation of .200 or more. The first characteristic was children with a primary visual condition of CVI, $r(500) = .248$, $p = .000$. This positive relationship indicated that children with a visual diagnosis of CVI were diagnosed at a later age than children with other visual conditions. The second variable was children receiving speech and language services as one of their EI services, $r(500) = .230$, $p = .000$. This positive relationship indicated that children receiving speech and languages services were diagnosed later than children receiving other EI services. The third and fourth individual variables with a strong correlational relationship with age of diagnosis are within the etiology variable: Children with vision conditions that occurred prenatally, $r(500) = -.233$, $p = .000$, and children with vision conditions that occurred postnatally, $r(500) = .210$, $p = .000$. The positive and negative relationships between age of diagnosis and prenatal or postnatal etiologies indicated that children who had prenatal visual conditions were diagnosed earlier than children with postnatal visual conditions. Appendix G lists all the Pearson correlations of each independent variable found to have statistically significant differences to both dependent variables age of diagnosis and age of referral.

Relationship Within Independent Variable Categories and Age of Referral

As with the variances between the many independent variables and the dependent variable age of diagnosis, the variance within the variables and age of referral were found with the same statistical procedure of ANOVA as part of a linear multiple regression procedure. Fewer variable groups were found to have significant differences, or variances, that suggest a relationship. The results indicated that out of 20 independent variables, only four variables demonstrated a statistically significant difference, or variances, related to age of referral. Those variable groups were gestational age at birth, etiology of eye condition, geographical location of state, and referral source.

Within the grouping of child characteristics, the independent variable groups of gestational age at birth, $F(4, 581) = 5.0.19$, $p = .001$, and the etiology of eye condition, $F(3, 582) = 5.411$, $p = .001$, were found to have statistically significance differences between the variables. Within the group of service characteristics, the variable group of state or geographical location, $F(4, 581) = 9.058$, $p = .000$, and the variable group of referral source to specialized visual impairment services, $F(3, 582) = 9.004$, $p = .000$, demonstrated statistically significant differences between the variables.

There was not a variable group within the category of family characteristics that demonstrated a statistically significant difference in variance with its relationship to the dependent variable age of referral. This indicated that family characteristics, such as type of caregiver, primary language, ethnicity, presence of siblings, or parent education level, had no impact on age of referral. Table 26 highlights the results for those variables demonstrating significance to age of referral.

Table 26

ANOVA Results for Variable Groups with Relationship to Age of Referral

Variable group	*df*	*F*	*p-value*
Child characteristics			
Gestational age at birth	4, 581	5.019	.001
Etiology of eye condition	3, 582	5.411	.001
Service characteristics			
State	5, 581	9.058	.000
Referral source	3, 581	9.044	.000

Correlations of Independent Variables to Age of Referral

Only one individual characteristic or independent variable within the four variables had a correlational relationship to age of referral, demonstrated as a Pearson correlation of .200 or more. The characteristic was the referral source of medical professional to specialized visual impairment services, *r(584)* = -.209, p = .000. The negative correlation indicated that children referred by their doctor, including a pediatrician, ophthalmologist, or neurologist, were referred earlier than children referred by another source, such as their EI program. Appendix G lists all the Pearson correlations of each variable of the independent variable groups found to have statistically significant differences to both dependent variables age of diagnosis and age of referral.

Research Question 3

Q3 Which variables predict or explain the age of diagnosis of blindness or visual impairment and age of referral to specialized visual impairment services?

Prediction or Explanation of Age At Diagnosis with Multiple Regression

Multiple regression analysis was used to test which predictor variable significantly predicted or explained the outcome variables of age of diagnosis of a visual condition that leads to BVI and age of referral to specialized visual impairment services. R square, instead of adjusted R square, was reported because of the large sample size. R square was the amount of the prediction or explanation of the predictor variable (independent variable) on the outcome variable (dependent variable). When the R square value was multiplied by 100, a percentage of explanation value was revealed. An R square of .300, which is 30%, indicates a good fit; however, none of the predictor variables in the analysis reached good fit status with the outcome variables. Appendix H highlights the results for the multiple regression for all the variable groups and age of diagnosis.

The results of the multiple regression found seven predictor variable groups that significantly predicted or explained the outcome variable age of diagnosis. Those seven variables were primary eye condition, etiology of eye condition, additional medical condition, primary caregiver, state, type of EI service, and number of EI services.

Primary eye condition. The results of the regression indicated the predictor variable group of primary eye condition significantly predicted or explained age diagnosis with 10.3% of the variance, $R^2 = .103$, $F(7, 494) = 8.140$, $p = .000$. This variable group of primary eye conditions had three models that significantly predicted age of diagnosis. The first model, $R^2 = .062$, $F(1, 500) = 32.88$, $p = .001$, consisted of the eye condition CVI alone, which significantly explained 6.2% of age of diagnosis ($\beta = .248$, $p = .000$.). Also, the correlation between CVI and age of diagnosis was found to be a positive correlation, $r(500) = .248$, $p = .000$. The positive correlation indicated that children with CVI were diagnosed at a later age than children with other visual conditions. The second model, $R^2 = .079$, $F(2, 499) = 21.42$, $p = .002$, found that CVI ($\beta = .304$, $p = .000$) and miscellaneous eye conditions ($\beta = .143$, $p = .002$) together significantly explained 7.9% of the variance of age of diagnosis. In the third model, $R^2 = .092$, $F(3, 498) = 16.89$, $p = .000$, a combination of CVI ($\beta = .336$, $p = .000$), miscellaneous ($\beta = .172$, $p = .000$), and unknown eye conditions ($\beta = .120$, p = .007) explained 9.2% of the variance of the dependent variable of age of diagnosis. However, this third model also increased the positive impact of CVI on age of diagnosis, with a correlation of .304, $r(500) = .304$, $p = .000$. The positive correlation indicated that the diagnosis of CVI, miscellaneous eye conditions, and unknown eye conditions were diagnosed at later ages than ONH, ROP, structural, or retinal eye conditions.

Etiology. The predictor variable group of etiology also had two models that significantly predicted or explained age diagnosis. The first model, $R^2 = .054$, $F(1, 500) = 28.86$, $p = .000$, consisted of the variable prenatal etiology ($\beta = -.233$, $p = .000$) that significantly predicted or explained 5.4% of the variance of the age of diagnosis. Also, the correlation between prenatal etiology and age of diagnosis, $r(500) = -.233$, $p = .000$, indicated a negative impact of the predictor variable of prenatal etiology on the outcome variable age of diagnosis. This negative correlation indicated that children with prenatal visual conditions were diagnosed earlier than children with perinatal or postnatal visual conditions. The second model, $R^2 = .078$, F(2, 499) = 21.079, p = .000, included both prenatal (β = -.300, *p* = .000) and perinatal (β = -.167, *p* = .000) etiologies to explain 7.8% of the variance of the age of diagnosis. With the addition of perinatal to the model with prenatal, the correlation between prenatal and age of diagnosis increased, *r*(500) = -.279, *p* = .000. The negative correlation indicated that the age of diagnosis for the etiologies of prenatal and perinatal was earlier than postnatal etiology.

State. The predictor variable group of state also significantly predicted or explained age of diagnosis, R^2 .041, *F*(4, 497) = 5.340, *p* = .000, to explain 4.1% of the variance. The individual predictor variable of state of New Mexico, R^2 .025, *F*(1, 500) = 12.610, *p* = .000, significantly predicted or explained 2.5% of the variance within age of diagnosis, (β = .157, *p* = .000). These results also indicated a correlation of .157, *r*(500) = .157, *p* = .000. The positive correlation indicated that the age of diagnosis of children residing in the state of New Mexico was later than for those residing in other states.

Medical condition. The predictor variable of medical condition consisted of one model ($R^2 = .026$, *F*(1, 500) = 13.125, *p* = .000) to explain 2.6% of the variance of the age of diagnosis. It was found that neurological medical condition significantly predicted or explained age of diagnosis (β = .160, *p* = .000) with a correlation of .160, *r*(500) = .160, *p* = .000. The positive correlation indicated children with a neurological medical condition were diagnosed with a visual condition later than other medical conditions. Also, this correlation aligned with the correlation of CVI to age of diagnosis, as both are neurological in nature and are associated with a later diagnosis of visual impairment.

Primary caregiver. The predictor variable group of primary caregiver was found to significantly predict or explain age of diagnosis, $R^2 = .039$, $F(4, 497) = 5.047$, $p = .001$, to explain 3.9% of the variance. It was found that the individual variable of two biological parents, R^2 .023, $F(1, 500) = 11.522$, $p = .001$, significantly predicted or explained age of diagnosis ($\beta = -.150$, $p = .000$) and 2.3% of the variance. The correlation of two biological parents to age of diagnosis was -.150, $r(500) = -.150$, $p = .001$. The negative correlation indicated children with two biological parents were diagnosed earlier than other family structures.

Number of early intervention services. The predictor variable group of number of EI services also significantly predicted or explained age of diagnosis, R^2 .046, $F(4, 497) = 5.942$, $p = .000$, to explain 4.6% of the variance. The individual predictor variable of no EI service, R^2 .024, $F(1, 500) = 12.176$, $p = .001$, significantly predicted or explained 2.4% of the variance within age of diagnosis, ($\beta = -.154$, $p = .000$). These results also indicated a correlation of -.154, $r(500) = -.154$, $p = .000$, and the negative correlation indicated that the age of diagnosis of children receiving no EI services was earlier than children who were receiving EI services.

Type of early intervention service. The predictor variable group of type of EI services also significantly predicted or explained age of diagnosis, R^2 .077, $F(7, 494) = 5.859$, $p = .000$, and explained 7.7% of the variance. The individual predictor variable of speech therapy, R^2 .053, $F(1, 500) = 27.985$, $p = .000$, significantly predicted or explained 5.3% of the variance within age of diagnosis ($\beta = .230$, $p = .000$). These results also indicated a correlation of .230, $r(500) = .230$, $p = .000$, and the positive correlation indicated that the age of diagnosis of children receiving speech therapy was later than children receiving other types of EI services.

Prediction or Explanation of Age At Referral with Multiple Regression

The same multiple regression procedure for the outcome variable age of diagnosis was completed for the second outcome variable of age of referral to specialized visual impairment services. The results of the multiple regression found five predictor variable groups that significantly predicted or explained the outcome variable age of referral. Those five were primary eye condition, gestational age at birth, etiology of eye condition, state, and referral source. Appendix H highlights the results for the multiple regression for all the predictor variable groups and the outcome variable of age of referral.

State. The predictor variable group of geographical location state significantly predicted or explained age of referral, R^2 .59, $F(4, 581) = 9.058$, $p = .000$, and 5.9% of the variance. The results of the regression indicated that two models explained the variance. The individual predictor variable of New Mexico, R^2 .038, $F(1, 584) = 23.011$, $p = .000$, significantly predicted or explained 3.8% of the variance within age of referral ($\beta = -.195$, $p = .001$). The second model of significance, R^2 .057, $F(2, 583) = 17.753$, $p = .000$, explained or predicted 5.7% of the variance of the age of referral when the state of Washington was added to New Mexico. Residing in New Mexico significantly predicted or explained age of referral ($\beta = -.151$, $p = .000$), as did the residence in the state of Washington ($\beta = .146$, $p = .001$).

With the addition of Washington to the model with New Mexico, the correlation was decreased between New Mexico and age of referral to -.151, $r(586) = -.151$, $p =$

.000. However, the correlation between the predictor variable of Washington residency to age of referral had a positive correlation of .146, *r*(586) = .146, *p* = .001. The negative and positive correlations indicated that the age of referral of children living in the state of New Mexico was earlier than children living in other states. The age of referral for children living in the state of Washington was later than those living in other states.

Referral source. The predictor variable group of referral source significantly predicted or explained age of referral, R^2 .45, *F*(3, 582) = 9.044, *p* = .000, and 4.5% of the variance. The individual predictor variable of a medical provider as the referral source, R^2 .044, *F*(1, 584) = 26.724, *p* = .000, significantly predicted or explained 4.4% of the variance within age of referral, (β = -.209, *p* = .000). The correlation of the predictor variable medical referral to the outcome variable of age of referral was -.209, *r*(586) = -.209, *p* = .000. The negative correlation indicated children who were referred to specialized visual impairment services by a medical professional were referred earlier than those referred by another referral source, such as an early intervention program. Appendix H highlights the results for the regression models of significance for the outcome variable of age of referral and all predictor variable groups.

Primary eye condition. The predictor variable group of primary eye condition significantly predicted or explained age of referral, R^2 .035, *F*(7, 578) = 2.995, $p > .005$, and 3.5% of the variance. The results of the regression indicated that two models explained the variance. The individual predictor variable of miscellaneous eye condition, R^2 .018, *F*(1, 584) = 10.935, *p* = .001, significantly predicted or explained 1.8% of the variance within age of referral (β = .136, *p* = .001). These results also indicated a correlation of .136, *r*(586) = .136, *p* = .001, and the positive correlation indicated that the age of referral of children reported to have a miscellaneous eye condition was later than children with other types of eye conditions, except for those with structural eye conditions. The second model of significance, R^2 .028, $F(2, 583) = 8.352$, $p = .001$, explained or predicted 2.8% of the variance of the age of referral and included both miscellaneous and structural eye conditions. It was found that miscellaneous eye conditions significantly predicted or explained age of referral ($\beta = .122$, $p = .000$), as did structural eye conditions ($\beta = -.098$, $p = .001$). The correlations were both negative and positive, indicating that children with structural eye conditions, $r(586) = -.098$, $p = .000$, are referred earlier than children with miscellaneous eye conditions, $r(586) = .122$, $p = .001$.

Gestational age at birth. The predictor variable group of gestational age at birth significantly predicted or explained age of referral, R^2 .033, $F(4, 581) = 5.019$, $p = .001$, and 3.3% of the variance. The results of the regression indicated that two models explained the variance. The individual predictor variable of unknown gestational age, R^2 .021, $F(1, 584) = 12.235$, $p = .001$, significantly predicted or explained 2.1% of the variance within age of referral ($\beta = .143$, $p = .001$). The second model of significance, R^2 .032, $F(2, 583) = 9.545$, $p = .000$ explained or predicted 3.2% of the variance of the age of referral when the gestational age of full term was added to the unknown category. Full term gestational age significantly predicted or explained age of referral ($\beta = .110$, $p = .000$), as did unknown ($\beta = .172$, $p = .000$). The correlations are positive, which indicated that children born at full term, $r(586) = .110$, $p = .000$, or who had unknown gestational ages, $r(586) = .172$, $p = .000$, were referred later than children born pre-term or prematurely.

Etiology of eye condition. The predictor variable group of etiology of eye condition significantly predicted or explained age of referral, $R^2 = .027$, $F(3, 582) = 5.411$, $p = .001$, and 2.7% of the variance. The results of the regression indicated that two models explained the variance. The individual predictor variable of postnatal etiology, $R^2 = .018$, $F(1, 584) = 10.895$, $p = .001$, significantly predicted or explained 1.8% of the variance within age of referral ($\beta = .135$, $p = .001$). The second model of significance, $R^2 = .027$, $F(2, 583) = 8.080$, $p = .000$ explained or predicted 2.7% of the variance of the age of referral when the postnatal etiology of eye condition was added to the unknown etiology variable. It was found that postnatal etiology significantly predicted or explained age of referral ($\beta = .164$, $p = .000$), as did unknown etiology ($\beta = .097$, $p = .000$). The correlations are positive, which indicated that children with eye conditions which occurred after birth or during early childhood, $r(586) = .164$, $p = .000$, or who had unknown etiology, $r(586) = .097$, $p = .000$, are referred for services later than children with eye conditions that occurred before or during birth.

Violations of Assumptions for Regression

Because none of the predictor variables in the study reached good fit status with the outcome variables, a closer examination of the assumptions of regression was conducted. The first assumption needed for a successful multiple linear regression is the need for a sample size of 20 for each predictor variable. This assumption was met as the sample size was over 500. The second assumption is the need for normal distribution of the outcome variable, which was age at diagnosis of a visual impairment condition and age of referral to specialized visual impairment services. A test of normality was performed by looking at the Shapiro-Wilke statistic. The outcome variable of age of diagnosis was found not to be normally distributed (*W* = .860, *p* = .000). Also, the outcome variable of age of referral was found not to be normally distributed (*W* = .878, *p* = .000). Both of these results were significant, indicating that both outcome variables were not normally distributed. To account for the lack of normal distribution within both outcome variables, the adjusted R square can be reported. But since the sample size was over 20 for each variable, it met the requirement for the R square statistic to be reported. Regardless of the large sample size, a violation of normal distribution still occurred.

The third assumption is absence of outliers in all variables. It was found that outliers were present in each predictor variable. In the regression procedure for age of diagnosis, the primary eye condition had 12 outliers, etiology had 10, medical condition also had 10, primary caregiver had nine, state had 11, the number of EI services also had 11, and finally type of EI service had nine. In the regression procedure for age of referral, primary eye condition had four outliers; etiology had only one, gestational age at birth also only had one, and both state and referral source each had four. Each of these outliers were for the late age categories of 24 to 36 months at age of diagnosis and 28 to 33 months at age of referral.

No violation of the fourth assumption of multicollinearity was found, as there were no significant correlations found between the predictor variables. However, the fifth assumption of the presence of a linear relationship between each predictor variable and outcome variable was violated. With examination of the scatterplots of the regression between each predictor variable and the outcome variables, no linear relationship was determined for any of the relationships. The assumptions that were violated may explain the lack of a good fit between the predictor variables and age of diagnosis, as well as age of referral, and may have affected the robustness of the regression.

Research Question 4

Q4 How do the results from this study compare to the results reported in the 2013 Babies Count analysis (Hatton et al., 2013), including

a. Trends in child and service characteristics; and
b. Differences that may be relevant for EI service providers?

Prevalence of Eye Conditions

This current study found that the top three eye conditions that lead to uncorrectable visual impairment were CVI (*n* = 171, 29.1%), ONH (*n* = 64, 10.9%), and ROP (*n* = 50, 8.5%). Hatton et al. (2013) also found the top three most prevalent eye conditions to be CVI, ONH, and ROP, except the order was a little different. CVI was found to be the most prevalent, ROP was second, and ONH was third (see Table 27). These results continue the trend of CVI as the most prevalent eye condition for children with uncorrectable visual impairment. Also, it suggests that ROP is an eye condition with decreasing incidence as medical advances increase.

The other eye condition groups, including structural, retinal, albinism and other/miscellaneous, were in the same order in this study as the results from Hatton et al. (2013), indicating these conditions are not changing in prevalence. Children with structural eye conditions were third in prevalence for both studies. For the current study, structural eye conditions consisted of 6.4% (*n* = 38) of the sample and 8.0% (*n* = 467) for the past study. Retinal eye conditions were fourth in prevalence with 4.1% (*n* = 24) of the children for the current study and 5.6% (*n* = 327) in the past study. Children with albinism comprised 3.1% (*n* = 18) of the sample in the current study, with 4.5% (*n* = 264) in the past study. The other eye condition category consisted of miscellaneous eye conditions and comprised 22.4% (*n* =132) of the sample in the current study with 25.6% (*n* = 1501) in the previous study. Children with no visual diagnosis or an unknown visual diagnosis was a larger proportion of the sample in the current study (15.5%) compared to only 9.5% in the analysis by Hatton et al. (2013). Table 27 highlights the frequency and percentages of each eye condition group in the current study and the previous Hatton et al. (2013) study.

Table 27

Comparison of Prevalence of Eye Conditions

	Current study *n* = 588		Hatton et al. (2013) *n* = 5,865	
Eye condition	*n*	%	*n*	%
Cortical visual impairment	171	29.1	1480	25.2
Optic nerve hypoplasia	64	10.9	616	10.5
Retinopathy of prematurity	50	8.5	697	11.9
Structural	38	6.4	467	8.0
Retinal	24	4.1	327	5.6
Albinism	18	3.1	264	4.5
Miscellaneous	132	22.4	1501	25.6
Unknown diagnosis	91	15.5	513	8.7
Total	588	100.0	5865	100.0

Functional Visual Ability

The Babies Count database identified the categories of levels of functional visual abilities with a combination of acuity measurements or an estimation of acuity. The category of *meets the definition of blindness* (MDB) was defined as children with an acuity measurement of 20/200 or less. The category of *functions at the definition of* *blindness* (FDB) was defined as children with a possible neurological visual condition, such as CVI, where an acuity measure is not able to be obtained but the child functions as a child with an acuity measure of 20/200 or less. The category of low vision (LV) is defined as children with an acuity measure of 20/70 to 20/200. The last visual acuity category is normal or near normal/typical vision and defined as children whose vision appears to be within the normal limits for a child of the same age.

The term "legal blindness" is defined by the Social Security Administration as a central acuity measure of 20/200 in the better eye with correction, or a field loss of 20 degrees or less (20 CFR § 404.1581). This term is not used as an eligibility criterion for educational or EI services. However, this is the measurement Hatton and colleagues used in their analysis of Babies Count in 2013. They found that 60.2% of their sample were in the category of legal blindness, which then leaves the remainder of the sample, 39.8%, as not having legal blindness (Hatton et al., 2013).

This current study found the opposite results. By collapsing the categories of MDB and FDB into the category of legal blindness, 205 children or 34.5% of the sample would be considered legally blind, compared to 60.2% in Hatton et al. (2013). Also, the categories of LV and typical vision are not considered to be legal blindness, and these two groups totaled 383 children, or 65.1% of the sample, compared to 39.8% in Hatton et al. (2013). Table 28 compares the current study with Hatton et al. (2013) in frequency and percentages of children with legal blindness and those without.

Table 28

Comparison for Legal or Not Legal Blindness

Level of sight	Current study (n = 588)		Hatton et al. (2013) (n = 1739)	
	n	%	*n*	%
Legal blindness	205	34.9	1,047	60.2
Not legal blindness	383	65.1	692	39.8
Total	588	100.0	1,739	100.0

Presence of Developmental Delays

The construct of disability or developmental delay concurrent to the visual impairment was measured very differently between Hatton et al. (2013) and the current study. Hatton and the co-authors (2013) had three indicators of the presence of additional disabilities. They included visual impairment only, developmental delay, and additional disabilities, though the level of these categories was not defined. While the category of developmental delay was not defined, it was coded to be a delay in one developmental domain such as a cognitive delay. Also, the category of additional disabilities was coded to be a delay in at least two or more developmental domains concurrently, such as a cognitive, physical (gross or fine motor), language, social, and/or adaptive delay, or a disability with more significance. This interpretation loosely aligns the constructs of Hatton et al.'s (2013) categories of presence of visual impairment only, developmental delay, and additional disabilities to the current study's variable of level of support needs as typical, mild to moderate, and intensive.

Across all eye condition groups, the current study found 13.8% (n = 81) of the sample had typical support needs, 50% (n = 294) had mild to moderate support needs, and 36.2% (n = 213) had intensive or complex support needs. However, Hatton et al.

(2013) had more equally distributed groups with 34.7% (*n* = 2033) visual impairment only, 28.3% (*n* = 1660) developmental delayed, and 37% (*n* = 2172) with additional disabilities.

For eye condition groups individually, the frequency and percentage of level of support needs or presence of additional disabilities were reported within each group. In the typical support needs and visual impairment only category, both this study and Hatton et al. (2013) reported the eye condition of albinism as the grouping with the largest percentage of children with typical support needs, with 50% (*n* = 9) and 86% (*n* = 227) with visual impairment only in Hatton et al., (2013). Regarding the smallest percentage of children with typical support needs or visual impairment only, 20 (11.7%) children in the current study were reported to have CVI and typical support needs while also in Hatton et al. (2013), 15% (*n* = 216) of the children with CVI had visual impairment only. The current study reported the unknown eye condition group had five children (5.5%) with typical support needs and the miscellaneous group had 14 children (10.6%), and in Hatton et al. (2013) both of these eye condition categories had much higher percentages; the unknown eye condition group had 28% of the sample with visual impairment only (*n* = 143) and the miscellaneous group had 33% (n = 495). The other groupings within children with typical support needs includes ONH (*n* = 14, 21.9%), ROP (*n* =5, 28.0%), structural conditions (*n* = 9, 23.7%), and retinal conditions (*n* = 5, 20.8%). For children with visual impairment only in the study by Hatton et al. (2013), the percentages of these eye condition groups are larger than the current study. There were 307 (50.0%) children with ONH, 231 (33.0%) children with ROP, 237 (51.0%) children with a structural condition, and 177 (54.0%) children with a retinal condition. Overall, the study conducted by Hatton et al. (2013) reported that 34.7% (*n* = 2033) of the sample were children with visual impairment only, which is more children than in the current study with typical support needs (*n* = 81, 13.8%).

For the middle category within the hierarchical structure, the current study found more children with mild to moderate support needs (*n* = 294, 50.0%), than Hatton et al. (2013) found with developmental delays (*n* = 1660, 28.3%). Six out of eight eye condition groupings, including unknown diagnosis (*n* = 57, 62.6%), ROP (*n* = 31, 62.0%), miscellaneous (*n* = 73, 55.3%), ONH (*n* = 32, 50.0%), structural conditions (*n* = 19, 50.0%), and albinism (*n* = 9, 50.0%), had a percentage equal to or greater than 50% reported as having mild or moderate support needs. Two eye condition groups were less than 50% but more than 30%, and they included CVI (*n* = 65, 38.0%) and retinal conditions (*n* = 8, 33.3%). In contrast, Hatton et al. (2013) reported five out of eight condition groups under 30% of the children with developmental delays. They included children with CVI (*n* = 429, 29%), ONH (*n* = 162, 26.0%), structural conditions (*n* = 87, 19%), retinal conditions (*n* = 70, 21%), and albinism (*n* = 26, 10.0%). The three groups over 30% with developmental delays were ROP (*n* = 215, 31.1), miscellaneous conditions (*n* = 501, 33.0%), and unknown eye condition (*n* = 170, 33.0%).

The last category, of intensive support needs and additional disabilities, both studies were very similar. Overall results of this study found 36.2% (*n* = 213) of the sample was reported to have intensive support needs, while Hatton et al. (2013) found 37% (*n* = 2172) of their sample to have additional disabilities. Both analyses had the highest percentage as children with CVI; this study was 50.3% (*n* =86) and Hatton et al. (2013) was 56% (*n* = 835). Also, the lowest percentage were children with albinism; this study was 0% (*n* = 0) and Hatton et al. (2013) was only 4% (*n* = 11). As for the other eye conditions and their similarities. Only ROP and retinal conditions differed remarkably between the two analyses. ROP had 10% (*n* = 14) of the children with intensive support needs in the current study and 36% (*n* = 251) children with additional disabilities in Hatton et al. (2013). Retinal conditions had 45.8% (*n* = 11) of the children had intensive support needs in the current study and 24% (*n* = 80) in Hatton et al. (2013). The remaining eye condition groups did not differ by more than 10 percentage points. Table 29 demonstrates the percentages of support needs and presence of additional disabilities for both studies.

Table 29

Comparison of Presence of Developmental Delays: Current Study (n = 588) vs. Hatton et al. (2013) (n = 5,865)

Eye condition [rank]	Level of support needs *vs.* presence of additional disabilities							
	Typical *vs.* VI only		Mild/moderate *vs.* Developmental delay		Intensive *vs.* additional disability		Total	
	n	%	*n*	%	*n*	%	*n*	%
CVI [1]	20	11.7	65	38.0	86	50.3	171	100.0
vs. Hatton et al. (2013) [1]	216	15.0	429	29.0	835	56.0	1480	100.0
ONH [2]	14	21.9	32	50.0	18	28.1	64	100.0
vs. Hatton et al. (2013) [3]	307	50.0	162	26.0	147	24.0	616	100.0
ROP [3]	5	28.0	31	62.0	14	10.0	50	100.0
vs. Hatton et al. (2013) [2]	231	33.0	215	31.1	251	36.0	697	100.0
Structural [4]	9	23.7	19	50.0	10	26.3	38	100.0
vs. Hatton et al. (2013) [4]	237	51.0	87	19.0	143	31.0	467	100.0
Retinal [5]	5	20.8	8	33.3	11	45.8	24	100.0
vs. Hatton et al. (2013) [5]	177	54.0	70	21.0	80	24.0	327	100.0
Albinism [6]	9	50.0	9	50.0	0	0	18	100.0
vs. Hatton et al. (2013) [6]	227	86.0	26	10.0	11	4.0	264	100.0
Miscellaneous	14	10.6	73	55.3	45	34.1	132	100.0
vs. Hatton et al. (2013)	495	33.0	501	33.0	505	33.0	1501	100.0
Unknown	5	5.5	57	62.6	29	31.9	91	100.0
vs. Hatton et al. (2013)	143	28.6	170	33.0	200	39.0	513	100.0
Total	81	13.8	294	50.0	213	36.2	588	100.0
vs. Hatton et al. (2013)	2033	34.7	1660	28.3	2172	37.0	5865	100.0

Note: Visual impairment (VI), Cortical visual impairment (CVI), optic nerve hypoplasia (ONH), retinopathy of prematurity (ROP)

Ages at Critical Events

Both the current analysis and the previous by Hatton et al. (2013) explored three critical events related to the access to specialized visual impairment services within early intervention programming and the responsiveness of these services. The measurement used for each event in both studies was the age in months for each child. The first critical event was the age of a child diagnosed with an actual visual condition that had a high probability of resulting in permanent or uncorrectable visual impairment, otherwise known as *age of diagnosis*. The second event was the age of a child referred to specialized visual impairment services within EI programming, otherwise known as *age of referral*. The third event was when these specialized visual impairment services actually began, otherwise known as *age at enrollment*.

These three separate events were compared between the two studies. Overall, the current study found that the children in this study were found to be diagnosed with a visual condition later ($M = 7.2$) than the Hatton et al. (2013) study ($M = 4.9$). But then were referred and entered services faster than the earlier study with about a one month difference between means. There were also individual differences according to specific eye conditions. For CVI, the difference in the means for diagnosis was 2.7 months longer in the current analysis; however, the difference between the means for referral ($M = -2.1$) and entry ($M = -2.2$) indicated that the current study was about 2 months faster. The eye condition of CVI had the greatest differences in the means for all three critical events between the two studies. The other eye condition with the second greatest difference among the means of the three critical events was ROP. The current study had a mean age of diagnosis ($M = 4.5$) at 1.7 months later than Hatton et al. (2013) ($M = 2.8$), but an earlier age for both referral (*M* = -1.9) and entry (*M* = -1.7). The eye condition of albinism was the only eye condition with a later referral and entry age than Hatton et al. (2013), with 0.1 months later for both. Table 30 describes the mean ages for diagnosis, referral, and entry for both studies and the differences between the means.

Table 30

Comparison of Age at Critical Events by Visual Conditions

Visual Condition	Mean age in months		
	Diagnosis of visual condition	Referral to specialized VI Services	Entry to VI services
Cortical visual impairment	9.5	9.0	10.0
Hatton et al. (2013)	6.8	11.1	12.2
Difference between means	2.7	-2.1	-2.2
Optic nerve hypoplasia	5.7	8.6	9.6
Hatton et al. (2013)	4.2	8.2	9.4
Difference between means	1.5	0.4	0.2
Retinopathy of prematurity	4.5	8.2	9.6
Hatton et al. (2013)	2.8	10.1	11.3
Difference between means	1.7	-1.9	-1.7
Albinism	3.9	9.5	10.6
Hatton et al. (2013)	3.3	9.4	10.5
Difference between means	0.6	0.1	0.1
Structural disorders	3.3	6.4	7.2
Hatton et al. (2013)	2.2	6.9	8.1
Difference between means	1.1	-0.5	-0.9
Retinal disorders	6.6	10.1	11.2
Hatton et al. (2013)	4.8	10.7	11.6
Difference between means	1.8	-0.6	-0.4
Miscellaneous eye conditions	7.5	11.3	11.9
Hatton et al. (2013)	5.3	12.1	13.1
Difference between means	2.2	-0.8	-1.2
All conditions	7.2	9.5	10.4
Hatton et al. (2013)	4.9	10.5	11.6
Difference between means	2.3	-1.0	-1.2

Summary of Research Question 4

The comparison of the results of this study and previous analysis of the babies count database (Hatton et al., 2013) uncovered continuations of trends as well as some notable differences. One trend was the top three most prevalent eye conditions. In both studies CVI, ONH, and ROP were found to be most prevalent, however ROP and ONH were in a different order between the two studies. Cortical visual impairment continues to be the leading cause of uncorrectable visual impairment in young children with both studies finding over 25% of the sample with CVI (Hatton et al., 2013).

A notable difference between the two studies was the level of functional vision of the children in the sample. In the current study, only one third of the children were categorized as legally blind, but in the previous study more than two-thirds were. These results indicated opposite results for the prevalence of legal blindness in young children with BVI between the two studies.

A notable similarity between the two studies was the prevalence of additional disabilities. While the construct of additional disabilities was measured differently in each study, one result was still very similar. In both studies, more than one third of the children had multiple disabilities (Hatton et al., 2013) or had intensive or profound support needs. But a noticeable difference was in the percentage of children with no additional disabilities or identified as having a visual impairment only. Hatton et al. (2013) identified more than one third of their sample as being only visually impaired compared to the current study finding half that percentage.

Regarding the comparison of critical events (age of diagnosis and age of referral), the results found that diagnosis of a visual condition occurred at later ages than Hatton et al, 2013. But generally, the children within the current sample were referred for specialized visual impairment services earlier than the previous sample. Only the visual conditions of ONH and albinism were referred later than the previous study, but only by less than two weeks to few days. A potential increase of responsiveness and accessibility of specialized visual impairment services were found within the sample of the current study.

CHAPTER V

DISCUSSION

Summary of Study Results

This study utilized a secondary data based called Babies Count to identify unique characteristics of young children with blindness and visual impairments (BVI). These characteristics were meant not only to define the population of young children with BVI and identify important trends, but to examine them related to responsive early intervention (EI) supports and services. The study looked at these characteristics through four research questions.

The first research question identified the characteristics unique to children with BVI. The study found that the most prevalent eye conditions in the sample were cortical visual impairment (CVI), optic nerve hypoplasia (ONH), and retinopathy of prematurity (ROP). Other trends or unique characteristics included a large presence of children with neurological visual and other medical conditions, as well as a high prevalence of additional disabilities in the sample. The children in the sample also were reported to have visual abilities, including vision as the leading primary learning channel, even though the children are also considered to have BVI. The mean age of diagnosis of a visual condition that leads to BVI was found to be 7.2 months of age and the mean age of referral to specialized visual impairment services was found to be 9.5 months. There was a mean gap of 5.2 months between age of diagnosis and referral.

The second research question examined more closely the relationship of the independent variables, or unique characteristics, on the dependent variables of age of diagnosis and referral. The study found that even though the results were not as robust as anticipated, a few key variables and characteristics were revealed as more impactful than others. For the dependent variable age of diagnosis, four independent variables were found to have relationships. These included the primary eye condition of CVI, postnatal etiology, and speech and language services that were found be related to later ages of diagnosis, and prenatal etiology, which was found to be related to earlier ages of diagnosis. Two independent variable groups (state and referral source) were found to be related to the dependent variable age of referral. Regarding referral source, medical provider was found to be related to an earlier age of referral, and EI program was related to a later age of referral. The state of New Mexico was found to be related to an earlier age of referral, while Washington state was related to a later age of referral.

To follow the second research question of relationships, the third research question examined the impact of the relationships between the independent and dependent variables to explain or predict the variance within dependent variables of age of diagnosis and age of referral. For the outcome variable of *age of diagnosis*, three explanatory predictor variables were identified. Those predictor variables included primary eye condition, which predicted 10.3% of the variance; etiology of vision condition, which predicted 8%; and type of EI service, which predicted 7.7% of the variance within age of diagnosis. For the outcome variable of *age of referral*, two explanatory predictor variables were identified. Those predictor variables included the variable group state, which predicted 5.9% of the variance, and referral source, which predicted 4.5% of the variance within age of referral.

The fourth and final research question sought to add to the existing knowledge base for identification and definition of the population of young children with BVI by comparing key unique characteristics to a previous analysis by Hatton et al. (2013) based on an earlier Babies Count database. The current and previous analysis found the same most prevalent eye conditions of CVI, ONH, and ROP, as well as the presence of additional disabilities in both samples, and similar ages at the critical events of age of diagnosis and referral per eye condition groupings.

Definition of a Population

The purpose of this current analysis was two-fold; define a population and measure the responsiveness of services designed to support the population. The first purpose was to assist the field of early intervention (EI) to define the population of infants and toddlers with blindness and visual impairment (BVI). The definition of a population that includes both its diversity and homogeneity is the foundation not only to identify the needs, but also to create a system of services to support those needs. A system of supports and services designed around the true needs of children with BVI and their families includes the development and implementation of direct or consultative service programs, and indirect programs such as university teacher/provider preparation programs. This exploration was able to clearly identify many common yet unique characteristics associated with individual children with BVI, their families, and the services designed to support them. A comparison of some of these identified characteristics to previous analysis completed by Hatton et al. (2013) begins to build a longitudinal look at the population and to identify trends meaningful to service providers. These unique characteristics include the trends of increasing neurological vision conditions and the presence of additional disabilities.

The changes and advances of the health field has changed the makeup of young children with BVI, which necessitates the educational field to update the descriptions of the educational needs of children with BVI. For example, the study detected the ongoing trend of a shift from ocular visual conditions as the primary cause of BVI to neurological visual conditions being more prevalent. Vision conditions that occur in the brain rather than the eye, including CVI and ONH, constituted more than 40% of the sample. Retinopathy of prematurity, which at one time was the leading cause of visual impairment, constituted 8.5% of the sample and dropped from second in incidence in the Hatton et al. (2013) study to third in the current results.

This evaluation of the current database was able to examine and compare the findings with previous analysis of an earlier database to create a longitudinal look at the trends or potential changes within the population of young children with BVI. The results found 86% of the sample to have additional special needs beyond BVI. Hatton et al. (2013) found 65% of their sample had additional needs. Even though there was a 20% difference, the comparison still shows the significant presence of additional needs within the population of children with BVI. It was outside the scope of the current analysis to determine if BVI causes the delays and disabilities, or if BVI exists concurrently with other delays and disabilities. However, young children with BVI do have a significant risk for additional learning challenges that must be addressed by both the teacher of the students with BVI (TVI) and other EI/early childhood educational professionals to appropriately support the whole child and family.

Another comparison between this study and Hatton et al. (2013) included examination of the severity of visual impairment, with opposite findings between the two studies. The current analysis found that 35% of the sample met or functioned at the definition of blindness, and the majority of the sample (65%) had low vision or vision considered typical for the child's age. Hatton et al. (2013) indicated that 60% had legal blindness and the remaining 40% did not. While it is difficult to measure the vision of infants and toddlers, especially those with additional disabilities and neurological visual impairments, it is unclear why the two studies had such different findings. More research is needed to look at the issue related to identification of level of functional vision due to assessment difficulty in this age group, the individual professional's ability to assess visual ability, or the construct of the measure between the two studies. The scope of this study did not explore these details.

In addition to level of vision, individual children's learning channels were examined, with the majority of children in the sample reported as being visual learners (57.7%), approximately one-third reported as auditory learners (30.3%), and the remaining small percentage of children reported as tactual learners (12.0%). The small percentage of children reported as tactual learners was surprising, considering that 35% of the sample were also reported as within the category of functioned at or met the level of blindness. Though some children were reported to have very little vision, they also might be visual learners. It is unclear if the potential discrepancy is due to either the complexity of sensory development (vision, tactile, and cross-modal means of accessing information) of young children or the inability of providers to identify tactual learning dominance in children who are very young and pre-readers. The results of the current analysis suggested an area of further research regarding the development of sensory modalities, as children move through their very early learning processes and development, especially tactile development, as a critical foundation for braille reading.

Almost one-fifth of the total sample, 113 children, were reported as having an unknown primary learning channel. With closer examination of those reported as having an unknown primary learning channel, it was discovered that 70% of those children resided in a state where over two-thirds of the specialized visual impairment services were not provided by certified TVIs, but provided by an employee of a specialized visual impairment agency. It was unclear if the certification of the service provider was related to how learning channel was reported, or if it was a philosophical decision regarding the accuracy of determining a primary learning channel for children under the age of three, but closer examination is probably warranted.

Regardless, the diversity of reported visual abilities and use of all sensory channels demonstrates the tremendous range of visual abilities and sensory channels used to access the world around young children with BVI. Especially important was the finding that children with BVI have vision, as 41% were characterized as having low vision and 57.7% were visual learners. Findings of the study accentuate the importance of the field of education for children with BVI to educate our EI partners on visual needs and its impact on development of the very diverse population of children with BVI. Those EI partners include occupational therapists, physical therapists, speech and language pathologists, and developmental special instructors who also supported over

90% of the sample. Over half of the overall sample received two or three EI services and 20% of the sample received four or more. Frequent presence of other EI services indicated that the majority of families within the sample have large EI teams consisting of three providers or more. The presence of many providers from many disciplines all supporting families of children with BVI, and especially those with additional disabilities, puts specialized visual impairment service providers, generally TVIs, at the center of the team. They are the essential team members because low or no vision impacts all developmental domains as the results in the analysis found over 50% of the sample were reported to have delays in five or more domains. When all providers practice with a family-centered approach, with consultation by the specialized visual impairment provider, the entire EI team can follow the lead of the family to understand the learning complexities of the child with BVI in order not to lose sight of the child as a whole person.

The complexity of needs and services also puts a high demand on the knowledge base of TVIs, especially those who work in the field of EI, beyond just the impact of vision loss on learning. So often the focus of the TVI is to address only the visual aspect of learning by providing accommodations and modifications to the curriculum. In the early developmental period, other sensory modalities are also critical to a young child's learning, such as the role of touch in the beginning stages of bonding and attachment with caregivers. Assessment of all sensory channels and learning media is equally as important for young children as it is for children who are school aged. The knowledge of how children are accessing their world, and the people within it, is critical for all ages and maybe more important for the very young child.

This study spotlighted the complexities of learning needs of children with BVI, including both neurological and ocular visual impairment, the presence of a range of additional disabilities, diversity of sensory channels, and large EI teams with multiple providers. It is imperative that the field of education for the BVI appropriately prepare providers to support those diverse needs, both direct and indirect, with both pre-service and in-service training.

Measurement of Responsiveness

When a system of services and supports is created, it is important for the field of education for young children with BVI to be able to measure the responsiveness of these supports, to insure the services are accessible to those who need them. The measurement of responsiveness of the specialized visual impairment services was the second purpose of the study through an examination of the characteristics related to child, family, and services on critical events of age of diagnosis and age of referral. A regression procedure was utilized to determine which child, family, or service characteristics were found to contribute to the explanation or prediction of the variance of both age of diagnosis and age of referral (outcome variables). Even though the results of the regression were not robust, and a good fit was not found among any predictor variables, possibly because of the number of assumptions that were violated, a few key variables were identified.

Three predictor variable groups contributed to the prediction or explanation of the variance of the outcome variable age of diagnosis. They were the variable groups of primary eye condition, etiology of eye condition, and type of EI service. The eye condition of CVI predicted or explained 6.2% of the variance with a positive correlation, meaning children with CVI were diagnosed later than children with other eye conditions. Additionally, prenatal etiology predicted or explained 5.4% of variance with a negative correlation, meaning prenatal eye conditions were diagnosed earlier than postnatal or perinatal conditions. These findings support the construct that the timing of the diagnosis of BVI was dependent on the type of eye condition, particularly whether the eye condition was neurological or ocular in origin. Ocular conditions that occur prenatally are typically easier to be recognized and identified by the medical provider. CVI is a neurological visual condition that may occur postnatally or after birth. Typically, CVI is identified when a child is not developing vision as normally as his or her same aged peers and an ocular reason for the lack of visual behaviors is ruled out as the cause. The findings support the paradigm of ocular and prenatal conditions being diagnosed before a neurological and postnatal condition.

Possibly another supporting finding for the difference in diagnosis between ocular and neurological vision conditions was the regression results for the variables type of EI service and number of EI services. As for type of EI services, the regression procedure found that children who were receiving other EI services predicted or explained 7.7% of the variance; specifically, speech and language services predicted 5.3% of the variance and were positively correlated to age of diagnosis, which may indicate children who received services from a speech and language pathologist were diagnosed with a visual condition later than children receiving other services. However, an even potentially more important finding than type of EI services was the number of EI services. Children who received no other EI service other than specialized visual impairment services were actually diagnosed earlier than children who received other services, as the predictor variable of no other EI service was negatively correlated to age of diagnosis. Therefore children with other learning needs, who may require speech and language services, are diagnosed with a visual condition later than those without additional learning needs and require only EI support due to their BVI. The important issue is that both types of children, those with only BVI and those with BVI and additional disabilities or delays, need specialized visual impairment services and should have equal access to appropriate services.

Approximately one quarter of the children in the sample, 25.8%, received a visual impairment diagnosis after referral for specialized visual impairment services. When looking closer at the individual visual conditions for age of diagnosis and referral, CVI was diagnosed later than all other vision conditions with a mean of 9.5 months, although children with CVI were referred for services at a mean of 9 months. CVI was the only vision condition where the average age of referral was before the average age of diagnosis. Referral prior to diagnosis may have occurred because EI teams identified vision concerns and referred for specialized VI services before an official diagnosis was given by a doctor. The visual conditions identified earliest were structural conditions at 3.3 months, albinism at 3.9 months, and ROP at 4.5 months, those that are visible or obvious, and yet referral did not occur for three to six months after diagnosis. The mean age of diagnosis for the entire sample was 7.2 months, yet the mean age of referral was 9.5 months, with differences in both events for all the visual conditions (see table 30). The mean time between age of diagnosis and referral was 5.2 months. The average age of diagnosis found in the current study was almost three months later than the previous study by Hatton et al. (2013), but the average age of referral was one month earlier. The finding may indicate that the field is becoming more responsive, as children and families are receiving access to services earlier, however, more longitudinal data are needed to make this determination.

Age of referral may be a more essential measurement of responsiveness than age of diagnosis to the accessibility of supports. The standard of 30 days between diagnosis of an eye condition that may lead to a visual impairment and the referral to specialized visual impairment was established by the National Agenda for the Education of Children with Visual Impairments, Including those with Multiple Disabilities (Huebner et al., 2004). The results indicated that referral of children with a diagnosed visual impairment to specialized services was far beyond the 30 days standard.

The analysis also examined the variables that may explain or predict age of referral to specialized visual impairment services. Knowledge of the variables related to early or late referral is essential to improving the responsiveness of the field of both EI and BVI to address the learning needs of children with BVI. For example, referral source was a significant finding related to age of referral. A medical provider as the referral source explained or predicted 4.4% of the variance of age of referral. Additionally, medical provider as referral source was negatively correlated to age of referral, indicating that children were referred earlier by their doctor than children who were referred by another source. The findings of early referral by medical providers was remarkable, especially because only 16.7% of the sample was referred by a medical professional and the large majority, 77.7%, was referred by the general EI program.

When the average ages of referral between referral sources were examined, the average age of referral for EI program was 10.2 months and the average age of referral by medical providers was 6.2 months. This difference indicates 4 months' mean difference between the referral sources of EI program and medical provider, with medical providers referring earlier than EI program. When a closer look at exactly who was the medical provider, 40 out of 98 or about 40% were pediatric ophthalmologists, but about 30% were hospitals, NICUs, social workers, or discharge nurses.

Since prenatal eye conditions, typically ocular, are being referred before postnatal, typically neurological, eye conditions, it may be questionable about ophthalmologists' ability to recognize a neurological visual impairment. While ocular impairments are much more identifiable and ophthalmologists are highly trained in ocular impairments, they may not fully understand atypical visual development or the risk factors associated with neurological visual impairments in order to identify a possible neurological visual impairment or CVI. It is also unclear if medical providers are familiar enough with the EI services in their community to refer children and families to the appropriate resource. The small number of referrals from doctors may indicate that they are not, but those who are familiar with community resources did refer earlier than even the EI programs.

When doctors miss or do not identify neurological visual impairments, EI providers should be able to screen to identify visual concerns related to development, which includes identifying medical risk factors associated with neurological visual impairments, such as a history of brain injury or malformation. Early identification by both medical and EI provider is important and typically the first point of access to specialized visual impairment services. The solution may be a public health approach to identifying both the developmental concerns about a child's vision and the community resources available to address the concern. Equal partnerships and effective collaboration is needed across all fields of medical and educational services, specifically the specialized BVI service providers, EI agencies and providers, and medical providers, including pediatricians, ophthalmologists, and neurologists. These partnerships should focus on education within and among all systems for knowledge and information regarding educational support after a medical diagnosis, or identification of need, and the location of the specialized visual impairment service.

Collaboration with EI partners is very important in order to assist them to accurately identify the learning needs related to low vision and blindness. This study provided results that emphasize collaboration is needed because EI programs were the most prevalent referral source, at 78% of the sample, yet EI programs referred later than medical professionals. It was outside the scope of the current study to examine the specific reasons for the later referral from EI providers to specialized visual impairment services, but it does raise the question whether EI providers have the skills necessary to screen for and identify vision issues in order to refer when needed.

On a positive note, when the age of referral is compared between children with BVI from this sample to the average age of referral of all children into EI, children with BVI are referred earlier than others. According to the current report by the Infant and Toddler Coordinators Association (2017) and its annual survey of state challenges, the average age of referral ranged from 12 months to 30 months, with an overall mean of 17.9 months. It appears that most children with BVI are being referred for EI services earlier than children with other disabilities or delays, possibly because eligibility for EI is related to BVI as an established medical condition that is identified by doctors and educational providers at a very early age.

The variable of geographical location related to age of diagnosis and referral offers more questions for future research to determine why there were differences among states. The answer may lay in both the medical system and EI system within those states. The variable of state was significant for both age of diagnosis and age of referral. The state where a child resided explained or predicted 4.1% of the variance within age of diagnosis, with New Mexico contributing to 2.5% alone, and 5.9% for age of referral, with New Mexico and Washington together contributing 5.7% of the variance. New Mexico was positively correlated to age of diagnosis but negatively correlated to referral, with Washington positively correlated to age of referral. Children in New Mexico are referred earlier than children in other states yet are diagnosed later. Furthermore, children in Washington are being diagnosed and referred later than children in other states.

There was great variability among each state in the study, especially related to factors such as the partnerships that exist within the system of BVI providers, EI programs, and medical providers. Each state has differing EI eligibility determinations. New Mexico, Washington, Maryland, and Utah all define eligibility for EI services as 25% delay or one standard deviation below the mean in one or more developmental domain. California defines EI eligibility as a 33% delay in one developmental domain if 24 months or younger and a 50% delay in one area or 33% in two areas, if 24 months or older. New Mexico is an “at risk” state, meaning children can qualify if they have an environmental or a medical/biological risk for a developmental delay (Early Childhood Technical Assistance Center, 2015). All states include established medical conditions, such as a visual condition, that will lead to a disability as an eligibility category. Many children with BVI are found eligible for EI services under established medical condition, but only if the visual condition is diagnosed prior to referral.

Additionally, some states may have added criteria to qualify for specialized VI services within the EI system and assert that a child must have a documented visual impairment by a doctor first. The specific visual impairment services eligibility for each state in the study was not known, however if a documented visual impairment is needed first, that criteria may delay the accessibility of services and also be against the IDEA definition of BVI eligibility for special education services as interpreted by the US Department of Education, Office of Special Education Programs (Ryder, 2017). A large percentage of the sample in New Mexico (42.2%) received a diagnosis after referral for services and New Mexico recorded the earliest referral rates. These early referral rates may be due to an eligibility criteria based on a concern rather than medical documentation. On the flip side of this policy is that it may assist programs to provide the services to only those who truly need them. Results indicated that 15.5% of the sample did not have a diagnosis of a vision condition and 24% of the sample was reported to have typical or near typical vision. These findings raise a concern about finding the balance between accessibility of services and serving only those who actually need the services.

Limitations

The limitations of this study are related to issues associated with using a secondary database as the source of data. The analysis utilized an existing database called Babies Count, which is a national database of infants and toddlers with BVI. At this point in time, only five states have contributed data for analysis. Respondents, who were specialized visual impairment service providers, completed a 37 question data collection form to gather information on a child, the family, and EI services at entry to services and again at exit from services. The large number of respondents across five states currently within the database caused a potential issue of fidelity, which raised reliability concerns. Even though the Babies Count data collection form includes clarification and guidance for answering all questions, it was not possible for the current study to assure inter-rater reliability or consistency prior to data analysis.

Demographic information was not obtained for the specialized visual impairment service provider completing the data collection form, however one question was included to identify the type of specialized visual impairment service provider. The question on the data collection form prompted the respondent to self-identify as a state certified TVI, orientation and mobility specialist, non-certified early childhood provider employed by a vision specific agency, deaf-blind specialist, or vision rehabilitation counselor. These providers all have different training, knowledge, and expertise regarding young children with BVI, and may contribute to the variation in responses to some questions, such as level of visual ability, primary sensory channels, and presence of developmental delays.

Many of the questions related to the child’s visual, medical, and educational characteristics are subjective measurements that depend on the expertise of the respondent. Conversely, the questions related to family and service characteristics were objective measurements based on factual information. These objective family and service characteristics measurements did not eliminate the issue of missing responses or errors within the database. Many questions were “unknown,” especially for family information, which may explain why all but one family characteristic did not show “good fit” within the regression procedure.

In addition to limitations related to fidelity and inter rater reliability, this study was affected by a potential sample bias. Not all young children with BVI were included in the database, as not all children with BVI received specialized visual impairment services, nor did they receive these services from a state/agency/provider that participated in the Babies Count project during the time of the study. The sample must therefore be considered a convenience sample. The sample may not be representative of the population of all infants and toddlers with BVI, as a limited number of states participated and represented a few highly committed agencies that provide EI services to young children with BVI. The sample included 588 children with BVI from five states and was compared to a larger sample of 5,865 children with BVI from 28 states in Hatton et al. (2013). Though the current sample was only 10% of the previous sample, similarities were apparent, such as primary eye condition and presence of additional disabilities.

Even though the Babies Count database and data collection form has been around since 1995, the data collection form was updated in 2015 and some questions were changed. (Appendix B details the changes.) Many questions were just minor edits and clarifications and some were complete changes of measure constructs. One major change was how children’s visual abilities were recorded. Previously measurement of actual visual acuity was recorded and an identification of legal blindness was asked. The measurement of level of functional vision was changed to align with the American Printing House for the Blind classifications for federal quota registry and asked if the child met the qualification of “meets” or “functions at the definition of blindness.” The study attempted to compare the two different measurements and was confronted with opposite findings between the two studies regarding the level of vision of the samples.

The opposite findings between this study and Hatton et al. (2013) demonstrate a potential issue in reporting. It was unknown if reporting difference was due to the inability of survey respondents to understand the new measurement of level of vision, or if more children really do have more visual abilities than in the previous analysis. More research may be needed to explore this issue.

Demographic variables regarding gender, ethnicity, language, parent education, and family structure were not changed on the new data collection form and could be compared between each study and the U. S. Census Bureau (2016). The comparison found that the current sample may have been representative, or at least very comparable, to the previous sample and the general population, within a few percentage points. Gender was found to be almost equal between the current study and Hatton et al. (2013), with both studies having more boys than girls in the sample. However, more females are found in the general population. As for ethnicity, the U. S. Census (2016) reported more White/Caucasian people than the current study and Hatton et al. (2013), but by only a few percentage points. Both the current study and Hatton et al. (2013) reported more children who were Hispanic than the U. S. Census (2016). The results found nine percentage points more children with Hispanic heritage than the U. S. Census (2016) and five percentage points more than Hatton et al. (2013), although the difference may be due to New Mexico being one of five states in the current sample. New Mexico reported 45.8% of its sample to be Hispanic/Latino and the U. S. Census (2016) reported 18%. Lastly, this study and Hatton et al. (2013) reported fewer Black/African American children than the U. S. Census (2016): 7% of this sample were Black/African American, while the U. S. Census (2016) reported 13%. There were many differences related to ethnicity reported in the sample from the five individual states. See Appendix F for individual state ethnicity proportions in the sample for the current study.

Hatton et al. (2013) did not report primary language in their demographics. Current analysis reported 79% as primary English speakers and the U. S. Census (2016) reported 82%. Family structure was not reported in the Quick Facts from the U. S. Census (2016), but this study reported 74% of the sample had two parents, and Hatton et al. (2013) reported 78% of their sample had two parents. Education level of adults was reported within the U. S. Census (2016), and mother's educational level was reported in both this study and Hatton et al. (2013). Hatton et al. (2013) and the U. S. Census (2016) both report 87% of the sample with a high school diploma or higher; this study reported 91%. The reported percentages for an educational level of a college degree or higher was almost the same, as this study reported 31%, the U. S. Census (2016) reported 30%, and Hatton et al. (2013) reported 27% of the sample with a college degree or higher. These results indicate that even though both the current and previous analysis utilized a convenience sample, both were still representative of the general population when compared to the U. S. Census (2016). See Table 31 for comparison between this study, Hatton et al. (2013), and the U. S. Census (2016).

Table 31

Comparison of Demographics for Representativeness of Sample

Characteristic	Current analysis	Hatton et al. (2013)	U. S. Census (2016)
	%	%	%
Gender			
Male	52	55	49
Female	48	44	51
Ethnicity			
White/Caucasian	49	57	61
Hispanic/Latino	27	22	18
Black/African American	7	8	13
Other	15	12	8
Language			
English	82		79
Non-English	18		21
Parent education			
High school or higher	91	87	87
College degree or higher	31	27	30
Family structure			
Two parents	74	78	
Other	26	21	

Note: Percentages are rounded to the nearest whole number.

Implications

The over-arching outcome of this study is that young children with blindness and visual impairment (BVI) are complex. This complexity was indicated not only in the visual and developmental needs of these children but also in the early intervention (EI) services designed to support them. The three most prevalent eye conditions of cortical visual impairment (CVI), optic nerve hypoplasia (ONH), and retinopathy of prematurity (ROP), as well as the high occurrence of additional disabilities or delays within the sample, denote the complexity and diversity within the population of children with BVI.

This complexity within the population of young children with BVI is the greatest implication for the field of education for the BVI in general, as infants and toddlers will grow up to be students in school. This study forecasted the future definition of the population of school-age students with BVI.

Implications Directed to University Preparation Programs

Cortical visual impairment was indicated as the most prevalent eye condition in the sample. When the secondary condition of CVI was combined with the reported primary condition, it increased the overall incidence of CVI to over one-third of the overall sample. The second most prevalent eye condition of ONH consisted of 10% of the sample. Over half of the sample was reported to have a neurological medical condition, and over one third had a feeding problem. Both of these visual and medical conditions are incredibly complicated disorders that have individual implications for each child. Children with CVI and ONH are highly idiosyncratic, as both the visual condition and other developmental issues may present themselves very differently for each individual child. The same can be said for neurological medical conditions, as the brain is highly individualistic, and developmental implications depend on many factors, including time, severity, and location of injury or malformation.

With over half of the sample reporting a neurological medical condition, this may explain the high occurrence of the presence of additional disabilities. Almost 40% of the sample were reported to have developmental delays in all six domains, but only 14% of the sample were reported to have no delays and typical support needs. Half of the sample had mild to moderate support needs and over one-third had intensive or profound support needs. This indicates that in addition to being visually impaired, the sample experienced a variety of special needs, and this diversity of support needs is another indication of the complexity of the population of children with BVI. The field of education for students with BVI needs to prepare teachers and orientation and mobility instructors for the comprehensive needs of these students who are BVI but may also have additional special learning needs. In addition, as children continue to age and grow out of childhood, the field of adult services also needs to prepare for the change toward an increasing population of transitional students and adults with BVI and additional disabilities.

The findings of large numbers of neurological impairments and the presence of additional disabilities in the sample should indicate to the field the increasing multiplicity of knowledge and information needed by our TVIs/O&Ms to provide instruction to all students with all levels of educational abilities. Implicit bias towards children with ocular conditions and typical development over neurological visual conditions, such as CVI and possibly moderate to severe additional disabilities, needs to be addressed, regardless of how denied and overlooked the bias may be. A necessary change of paradigm is needed for TVIs and O&M specialists to expand their view of instructional needs of all students with BVI, including those with additional disabilities. It is important for all TVIs to address all areas of the expanded core curriculum beyond traditional academic skills focused on braille and include appropriate accommodations and modifications for children with CVI, for instance.

A focus on teaming and partnering with other educational providers is a critical component for access to appropriate learning opportunities across the continuum for students with BVI. A multiple disciplinary team approach is important for all students with BVI but especially those with additional disabilities, including infants and toddlers.

Children under the age of three, who have not entered the school system and often have additional disabilities concurrent with BVI, also should have equal access to highly qualified and competent specialized visual impairment service providers. However, often young children with BVI and students with BVI and concurrent disabilities do not receive the same level of service as their peers with BVI only and academic needs. Inequality is primarily due to the personnel shortages within the field of education for children with BVI, but often the TVIs who are available are poorly trained and not competent or confident in their skills to teach beyond the vision-only issues related to instruction. It is critical for the field to address these inadequacies in the workforce and assure that all children, regardless of age or presence of additional disabilities, have equal access to appropriate services and supports to meet their individual learning needs.

The inquiry of sensory modalities underscored an area of needed instructional and informational support regarding the early development of all sensory modalities, especially tactual development, since tactual learning was reported as the primary learning channel for only 12% of the sample. The tactile sense is a near sensory function, with vision and hearing as distance senses, and touch is the first sensory modality to develop while babies are still in utero. The tactile sense is required at a very early age for bonding and attachment, as well as the first form of communication or response to the environment. But not much is known about the development of the important modality of touch, especially if vision is absent or impaired, nor how it can be developed and understood by those closest to the infant.

The curriculum in university teacher preparations programs are not only typically geared to the school aged child, but also heavy in content focused on visual accessibility.

Tactile development is taught only for braille instruction. There appears to be another implicit bias towards visual development over tactual sensory development. Future teachers are taught to preform evaluations such as the Functional Vision Assessment but are not always taught about the importance of assessing the development or measurement of progress of the tactual sensory channel. The Learning Media Assessment is also taught, and sometimes it includes a sensory learning profile, but the assessment in general is meant to determine reading medium and not the development of senses in very young children who are pre-readers. The American Printing House for the Blind reported in its Federal Quota Annual Report that only 8% of the students of all ages with BVI counted were braille users (American Printing House for the Blind, 2017). Wall and Corn (2004) also found 7% of students with BVI in Texas were braille readers. These results may indicate that many children with BVI have multiple disabilities and not the ability to read braille; it also may indicate that a focus on the development of the tactual system at infancy would lead to an increase in braille competency. Early tactile development connected to braille readiness is certainly an area worthy of more research.

Implications Directed to Early Intervention Systems

To add to the diversity of sensory abilities of children with BVI, the findings uncovered that many children with BVI have visual abilities and are reported to have vision as their primary learning channel. Almost half of the sample were reported to be visual learners, and only one-third of the sample were reported as having a significant visual impairment as indicated by the categories of meets or functions at the definition of blindness. Often general EI providers or families misunderstand learning challenges related to BVI because the child can see. Often the ability to see is a misunderstood characteristic of the population of children with BVI by many with limited understanding of vision loss, including parents and EI providers. A misunderstanding of the visual abilities of children with BVI could lead to the child's visual impairment being under-identified. The child's visual impairment may not initially be identified as a learning need, nor a need with the highest concern for families or EI teams, as the child's physical, communicative, or adaptive (such as feeding/eating) delays are more apparent and easier to recognize. This inability to recognize the impact of vision loss on learning may cause families and EI providers to wait to refer for specialized visual impairment services, regardless of how minor the loss appears to be. But this wait may cause learning challenges to be increased as a critical need is not addressed due to the impact of BVI on other developmental domains. Again, the results indicated that not only is the diversity of children with BVI within the full range of developmental abilities, but also a full range of visual abilities. It is critical that EI providers have competencies in visual screening abilities, which include reviewing medical records for risk factors, interviewing families about history and concerns, and observing children performing associated developmental and visual behaviors. A comprehensive ability to identify visual concerns related to developmental delays may lead to an early referral to the appropriate supports and resources needed to assist the child and family.

The analysis found a significant delay of 5.2 months between the diagnosis of BVI and referral for specialized visual impairment services, possibly because the learning needs of the child with BVI have been misunderstood. While the study did not clearly define the reasons for the delay, it did uncover variables that may predict or explain the variance within age of diagnosis and age of referral, which might be due to the complexities of children with BVI and that other developmental needs are considered more critical of support. The visual condition of CVI alone contributed to 6.2% of the variance within age of diagnosis, and a positive correlation to age of diagnosis indicated that children with CVI are more likely to be diagnosed with a visual impairment later than children with other conditions. These results again stress the complexity of some children with BVI, especially those with CVI and a postnatal cause of visual impairment, compared to those caused prior to birth or at birth, as they may have more confounded learning and visual needs.

Implications Directed to Specialized Visual Impairment Services in Early Intervention

Geographical location, specifically state of residence, emphasized the complexities of the systems designed to support children and families. The predictor variable of state contributed to 5.9% of the variance in age of referral, with New Mexico and Washington as the two key states. New Mexico was negatively correlated to age of referral (children residing in New Mexico were referred earlier) and Washington was positively correlated (children residing in Washington were referred later) than children residing in the other states in the sample. The states of New Mexico and Washington have different systems of support services for young children with BVI. New Mexico has an established network through the state school for the blind and has many specialized visual impairment providers located throughout the state. Conversely, Washington is still in the beginning stages of a coordinated system of support, also through the state school for the blind, but the system is still fractured, and access to specialized visual impairment providers depends on the location of the child within the state. The comparison between an established and coordinated system and a new yet still fractured system may be the cause of the difference between the two states' mean age of referral. When the medical providers and EI partners know how to recognize a visual impairment and where to turn for support, then children will have responsive services. The system to provide the needed services must exist first. Once established, the specialized visual impairment service system is responsible for informing and educating both the medical and EI partners about the resources available to complete the cycle to meet the needs of children and families.

Regarding the types of services to support children with BVI and their families, the results again found great diversity and complexity within the support systems. While the majority, about 65%, of the sample received their specialized visual impairment services from a TVI or other certified professional for students with BVI, the other 35% received their services from a non-certified visual impairment professional employed by a specialized agency for children with BVI. These specialized visual impairment services, regardless of the type of provider, appeared to be based on a consultation model as they were mostly provided monthly or bi-weekly with only about 15% of the sample receiving weekly support.

As with a consultation model of service, many children in the sample received other EI services. Though the frequency of these related services is unknown, over half of the sample received two or three EI services, in addition to the specialized VI service, and 20% received four or more for a total of five team members when the VI professional is added. Less than 10% of the sample received EI services only from the VI professional. The findings indicated children with BVI have large EI teams and implied the tremendous responsibility of the specialized visual impairment professional to serve as coach or consultant to these other professionals on the impact of vision loss, both minimal and significant, on all developmental domains. It emphasizes the need for training for the specialized visual impairment provider, typically a TVI, in the transdisciplinary team based early intervention approach, including role release and coaching, as well as other practices critical for EI systems, such as routine-based and family-centered practices. A consultative relationship and strength-based approach of support provided to children indirectly through the primary caregivers can sometimes be difficult for teachers, who are trained in a direct instruction, child centered, or deficit model approach utilized in a special education school based system. Teachers of students with BVI, who work with families in the EI system, may need additional training, beyond their pre-service university training in visual impairment, to be an effective team member to best meet the global needs of children and families.

Summary of Implications

The implications of this study touch individual programs and states, but also reach into the entire field of education of students who are BVI. The first implication regarding the complexity of needs in young children with BVI, that includes a large proportion of neurological visual impairments, presence of additional disabilities, and large multiple disciplinary EI teams, puts added responsibilities on the specialized visual impairment service provider, typically a teacher of students with visual impairments. The TVI needs to have a broad range of skills in the instruction, including accommodations and modifications, to address the broad and global learning needs related to BVI in early childhood. But also the TVI within the EI system must possess added knowledge and skills in effective teaming strategies to work with families and other EI partners to support the whole child.

The second implication of addressing early identification and early access to specialized visual impairment services is also related to effective collaboration skills between the BVI community and partners in the medical and EI communities. Medical providers and EI programs are the access door for families of children with BVI for services that support the critical need of understanding the child's BVI and how it may impact the learning process. Alliance and cooperation between service agencies and referral sources are essential for information and knowledge sharing about availability and accessibility of the unique resources for children with BVI.

Lastly, this study highlighted the need of the field of education for students with BVI to prepare for the future. Babies will grow up to be students in schools. The preparation does not just include preparing future teachers for the educational and instructional complexity of all students, but also the complexities of the systems they work within that support students, families, general and special educators, adult rehabilitation counselors, and others to assist the child to reach full potential.

Recommendations for Future Research

Important areas for future research were identified by this exploration as the continuation of the original purpose of the Babies Count database. The implications indicate an ongoing need for the field of education of children with BVI to continue to define the population and the characteristics related to responsive services to meet the needs of children with BVI. Those areas include a continuation of the Babies Count project and database, examination of systems related to early referral of children with

BVI to specialized visual impairment services, and finally a closer look at sensory development in young children beyond a focus of visual development.

Critical data were uncovered related to the unique characteristics of the population of young children with visual impairments. However, it was just a brief snapshot of all that is potentially available to inform the field. With the continuation of the project it is hopeful that a longitudinal collection of information can continue to educate and inform the field about the changing nature of children with BVI, in order to provide appropriate services to children of all ages now and in the future.

In addition to increasing participation, the project needs to assure fidelity in data collection and maintain reliability of the data. Inter-rater reliability was attempted initially by including an instructional manual for guidance with each question. However, more instructional guidance may be needed to account for the diversity of respondents with regards to level of education, training, and experience that may impact completion of the data collection form with fidelity and inter-rater reliability. It is recommended that video training modules be produced and available on the Babies Count website for viewing by all participants in the project. Important modules to include should be focused on the subjective questions that require observation of child skills, such as level of visual ability, use of sensory channels, and identification of support needs, but also questions that involve interviewing families. Many of the family information questions were indicated or reported as unknown, but it is possible that the service provider/respondent was uncomfortable with asking the question. Training could be provided to increase providers' confidence when interviewing families.

The second area of future research is related to the system of early referral of young children with BVI to specialized visual impairment services and potential strategies needed to assist with early access for families. The results found that referrals made by medical providers and EI providers differed by a mean of 4 months. Medical providers referred with a mean age of 6.2 months, while EI providers referred at a mean age of 10.2 months. It was beyond the scope of the current study to examine these mean ages more specifically, such as a cross tab analysis of referral source and primary eye condition, presence of additional disabilities, level of vision, or primary sensory channel, and even relationships amongst the independent variables. More in depth quantitative and qualitative analysis of EI systems would be beneficial to help explain and provide solutions for the issues related to late referrals. A qualitative analysis could examine state and local systems related to the partnerships between specialized BVI services and the medical community as well as the EI partners. There may be a substantial amount of information that programs and agencies can learn from each other to further improve programming decisions related to quality services and support offered to families across geographical locations, such as an exploration of the system of vision screening procedures that have been found to be effective for the partnership and collaboration among EI programs and specialized visual impairment services.

The last research area is specific to types of services provided to young children with BVI around the instruction, modifications, and accommodations to encourage or assist with the development of all sensory modalities, specifically tactile development. Much is known about the visual development of young children, but less is known about tactile development. Much is also known about enhancing a child's use of vision in a home and school environment, but little is known about how to encourage the child's use of other sensory modalities for access to environmental exploration when vision is limited. Future TVIs are taught how to teach a tactile reading method (braille), but it is unclear how much pre-service content is focused on readiness skills and early tactile development of very young children with BVI. Since touch is an important mode of communication and connection to others from very early ages, touch may be an important component for the infant's mental health and should be addressed by the entire EI team. It is also unclear about the connection between braille competency and early tactile development. The relationship of early tactile development and learning to read a tactile medium may be an area that needs further exploration to assist with increasing the literacy rates in students with BVI, especially those who require braille for access to literacy materials. Increased knowledge about the value and use of all sensory modalities, especially touch, could lead to strong foundations for all service providers to assist in reaching full learning potential of children, as well as families' and other EI providers' understanding of the unique learning processes of children with BVI.

The research possibilities identified by this study are potentially endless due to a large database, however three key recommendations include (a) a continuation and improvement of the Babies Count project, (b) quantitative and qualitative examination of systems for early referral, and (c) a comprehensive exploration of tactile development in young children. These three key areas will continue to define the unique characteristics and needs of the population. Continuation of building the base of knowledge about the population is critical for implementation of services that appropriately support the true needs of children with BVI. The attention and focus of the changing population and its needs will enhance EI services for children with BVI, as well as educational services provided to children of all ages with BVI, and continue to improve the quality of services delivered by the entire field of education and rehabilitation for people of all ages with BVI.

Conclusion

The population of children with BVI is changing, and the current study assisted in updating the definition of this unique population of children. However, evolution is not new to the field of education for children with BVI, as many transformations have occurred over the past century. The field has a very long and varied history starting in the 1800s with the creation of schools for the blind (Spungin & Huebner, 2017). Primarily residential in nature due to the low prevalence of children who were blind, schools for the blind, both private and public state agencies, were the primary location of educational services for students. Then in the 1950s, a post war baby boom brought the field an influx of premature babies born with retrolental fibroplasia (RLF), now known as retinopathy of prematurity (ROP). These babies were primarily from upper middle class families who advocated for their children to attend local community schools instead of schools for the blind. This marked the first evolution for the field as children were beginning to be mainstreamed into local schools and creating the need for itinerant TVIs.

In the next decades, the definition of children with BVI was still primarily considered blind. However, in 1964 Natalie Barraga introduced to the field the concept of vision stimulation and strategies to enhance visual potential in children, which further expanded the definition of the population to include children with low vision (Spungin & Huebner, 2017). Now, today, the field is experiencing another change in definition for children with BVI that includes children with neurological visual impairments, rather than only ocular, and the presence of additional disabilities accompanying the visual limitations (Lueck & Dutton, 2015).

The definition of vision loss has expanded beyond only depending on acuity and field deficits to now also encompassing visual perception, attention, and motor deficits. This expansion was due to more attention to the brain as a critical component to the visual system with the eye. The attention to children with CVI began in the 1980s with the work of medical professionals like Dr. James Jan, who began to merge the medical and educational communities together for the benefit of children with BVI. Today this work continues with Dr. Christine Roman-Lantz, Dr. Amanda Hall Lueck, and Dr. Gordon Dutton, who have all utilized both the medical and educational fields to highlight the visual needs of children with neurological visual impairments, including assessment and instructional strategies to meet the educational needs of children with CVI and beyond (Lueck & Dutton, 2015).

Each time the population changed, the field responded, and this time should be no different. The population, which was once characterized with confined homogeneity of only children with blindness due to ocular conditions and no additional disabilities, is now comprised of the greatest diversity of visual and developmental abilities across the global span of children themselves. A change in the composition of the population, including diverse characteristics and learning needs, also has caused a change in the way the educational needs are addressed. Rather than educate this diverse population with one educational model, there are a full range of educational placements across the continuum, which spans from residential schools to local schools and from self-contained special education classrooms to full inclusion within the general curriculum.

In all of these educational settings, the specialized visual impairment educator, typically a TVI or O&M specialist, is the educator with specialized knowledge and information about the unique learning needs of the student with BVI. However, they are not the only educator for the student as in the past. Children with BVI are now being educated by many educational professionals, including special and general educators, as well as related service providers such as physical, occupational, and speech therapists. The analysis found that 85% of the sample had large EI support teams, and only 15% of the sample had one EI provider who was the specialized visual impairment provider.

As the diversity of characteristics of children with BVI increases, both developmentally and visually, the diversity of service provision also increases. This increase in diversity has caused the roles and responsibilities of the specialized visual impairment provider to multiply as well. The competencies for specialized visual impairment educational providers (TVIs/O&Ms) cross the spectrum from birth to 21 years of age, across developmental abilities from typical development to severe/profound disabilities, and across visual abilities from minimal visual impairment to total blindness. In addition to competencies related to direct instruction as a primary provider/teacher, competencies are also required to provide indirect services to children through the ability to appropriately coach or consult with other educational professionals and families. In a sense, TVIs and O&Ms are not only responsible for the education of the student with BVI, but also the education of other adults, both educators and parents.

An important component of the ability to educate others in the needs of children with BVI is to frame the roles and responsibilities of the specialized visual impairment provider as more developmental regarding all sensory modalities and singularly around the construct of vision only, or the ability to see or not. The focus of learning with only one modality, vision, sets up the very first barrier to others' understanding of the true nature of visual impairment and learning. Children with BVI are so much more than their visual abilities, and it is critical that the specialized visual impairment provider assist others in the view of the child as a whole person.

Additionally, the focus of an indirect consultation model versus a direct instruction model is even more critical for the specialized visual impairment service provider in EI as indirect services and supports are the cornerstone of family centered practices. The specialized visual impairment service provider, as the home visitor, affects child development through parents and not directly with the child (Roggman et al., 2016). Intentional training, both pre-service and in-service, for indirect service provision, specifically being an effective collaborator, consultant, and coach, is needed because these behaviors may not come naturally to some educators and are important competencies in the EI system. Direct instruction should not have more importance or significance over indirect and consultation services and is possibly another implicit bias in the field of education for the BVI. For children with BVI, both in EI and in school systems, consultation or indirect services through a routines-based approach may be more effective to encourage overall learning and developmental progress than direct teaching to the child.

The exploration looked specifically at the beginning of services with the access point or time that infants and toddlers with BVI entered into specialized visual impairment services. A gap of 5 months was found between the mean age of diagnosis of a vision condition and the mean age of referral to specialized visual impairment services. Two variables, referral source and geographical location, significantly contributed to the age of referral. There was a difference between the age of referral for the referral sources of a medical provider and an EI program, with the medical provider referring earlier than the EI program. The geographical location of state found that children who resided in New Mexico were referred earlier than other states, and those who resided in Washington were referred later. These results highlight the importance of partnership and collaboration between the specialized visual impairment program and both the medical and EI communities to lower the ages at which children with BVI have access to appropriate support services. Specialized visual impairment providers, such as the TVI in EI, can assist the EI program with vision screening procedures to identify vision concerns and also to understand the importance of identification. In addition, specialized visual impairment providers can assist the medical community to know the resources and supports available to families beyond the medical exam room.

This diversity and complexity, both with developmental and visual needs of young children with BVI and the services designed to support them, was demonstrated in the results and together have given a data driven direction to the improvement of services to the entire field of EI and overall educational system for children. This knowledge of the needs can directly be used by programs for young children with BVI to improve the partnerships with other programs. The complexity and diversity not only of young children with BVI, but also of the services designed to support them, gives the field great challenges to overcome. But this challenge also gives great opportunities for partnerships and collaboration with other educators and related service providers to meet the global needs of this unique population of children.

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APPENDIX A

TIMELINE OF BABIES COUNT: THE NATIONAL REGISTRY OF INFANTS AND TODDLERS WITH BLINDNESS AND VISUAL IMPAIRMENTS

Timeline of Babies Count: The National Registry of Infants And Toddlers with Blindness and Visual Impairments

Table 32

Timeline of Babies Count: The National Registry of Infants and Toddlers with Blindness and Visual Impairments

Year	Event
1995	Babies Count created by original Model Registry of Early Childhood Visual Impairment Consortium Group at the University of Northern Colorado after a demographic data collection process established at Blind Babies Foundation.
1996	Pilot phase of project. During pilot phase, data were sent to University of Northern Colorado for entry and analysis. Hilton-Perkins Foundation funded the 2 year pilot project.
1997	Original data collection form is finalized and distributed to programs in 9 states and 1 Canadian province. USDB created original database and served as first central repository. UNC-Chapel Hill agreed to analyze data and finalized first research questions.
1998	Data from January to December of 1998 was sent to Deborah Hatton for analysis. Poster presentation at International AER Conference in Atlanta, GA.
1999	Hatton analyzed the second set of data (January to June of 1999). Preliminary data shared at International Preschool Seminar meeting in Pacific Grove, CA.
2000	Presentation at Early Connections Conference in Vancouver, BC and also at International AER Conference in Denver, CO. APH takes on project as one of its Early Childhood Projects.
2001	Revisions made to the data collection form and new states signed up. APH begins data collection. Article written by Hatton (2001) on the first year (January 1998 to June 1999) results was published by JVIB. Included 9 original states with 406 babies in sample.

Table 32, continued

Year	Event
2007	Second publication of data analysis from January 2000 to December 2004 appeared in *Journal of American Association for Pediatric Ophthalmology* by authors Hatton, Schwietz, Boyer, and Rychwalski (2007). Included 2,155 babies from 29 states.
2011	APH relinquishes Babies Count.
2013	Third publication of data analysis from 2005 to 2013 in JVIB by Hatton, Ivy, and Boyer (2013). Included 5,931 babies from 28 states. International Preschool Seminar meeting participants discuss the desire to continue Babies Count and locates new administrative home of the project as NMSBVI. New Model Registry Taskforce begins work on revision of data collection form and instructional manual.
2014	Presentation at Council for Exceptional Children, Division for Early Childhood Conference (CEC/DEC) in St. Louis MO.
2015	New data collection form and procedures are complete with multiple stakeholder input from International Preschool Seminar meeting participants. Presentations at American Foundation for Blind Leadership Conference (AFBLC) in Phoenix, AZ and Western Regional Early Intervention Conference (WREIC) in Albuquerque, NM.
2016	New database and website available for data collection, www.BabiesCount.org, in March.
2016	Presentations at International AER Conference in Jacksonville, FL and International Council for Education of the Visually Impaired (ICEVI) meeting in Orlando, FL.
2017	First year results after revision will analyze data from March 2016 to March 2017. Partial results shared at International Preschool Seminar meeting in Illinois and Western Regional Early Intervention Conference in Arizona.

APPENDIX B

COMPARISON OF OLD AND NEW BABIES COUNT DATA COLLECTION FORM

Comparison of Old and New Babies Count Data Collection Form

Table 33

Comparison of Old and New Babies Count Data Collection Form

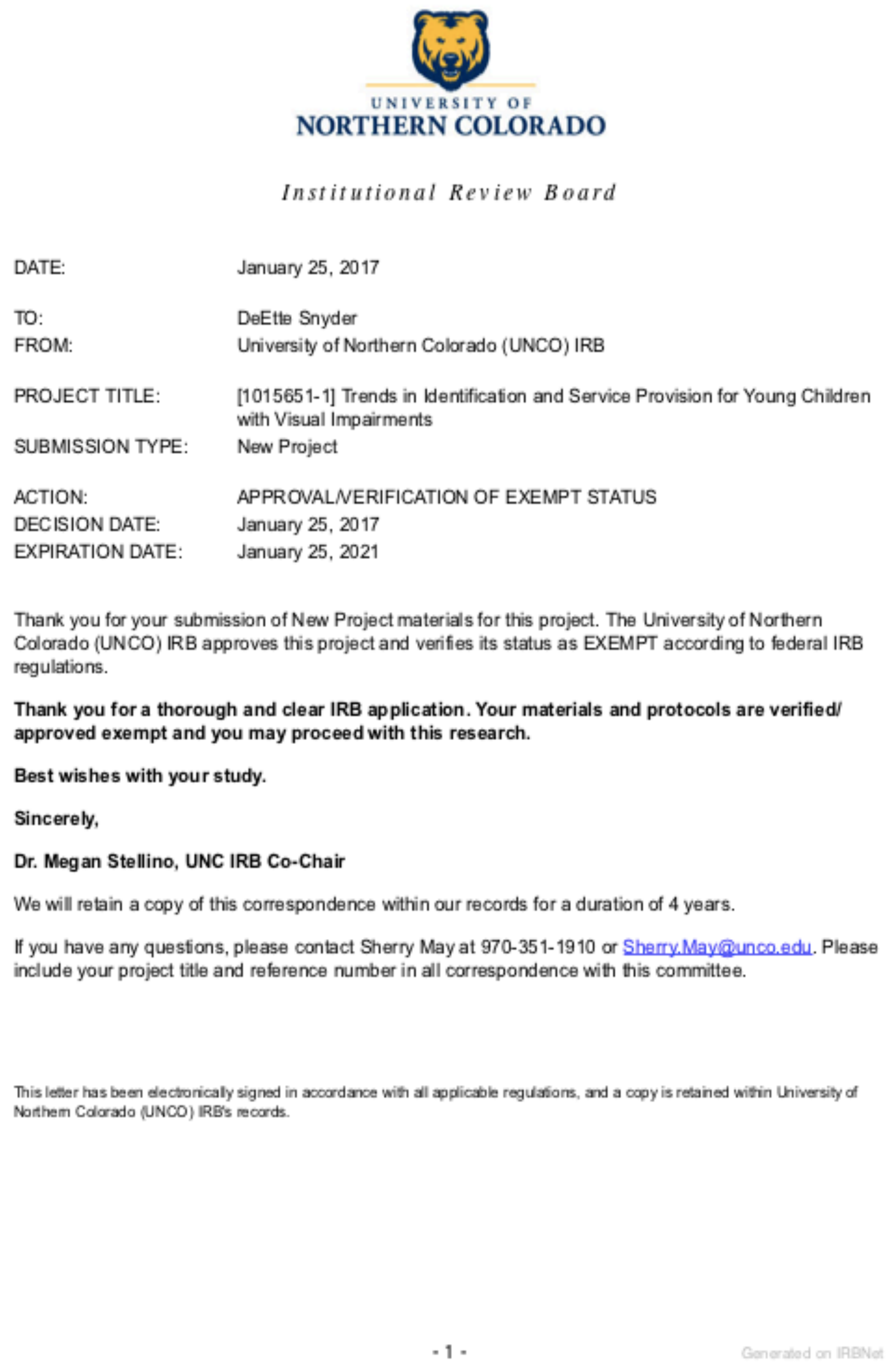
Old Form		New Form	
Item #	Description	Description	Item #
	Child Information	**Section Pre A: Identifiable Child Information**	
1	Program Identification	Gender	1
2	Gender	DOB	2
3	Ethnicity	Birth weight	3
		Section A: Child and Family	
4	State and zip code	Ethnicity	4
5	DOB	Gestational age at birth	5
6	Gestational age at birth	Multiple birth	6
7	Gestational information retrieved from	Bio Mom's age at birth	7
8	Birth weight	Bio Dad's age at birth	8
9	Multiple birth	Child lives with	9
10	Date or age of visual diagnosis	Primary Language	10
11	Referral date	Parent/guardian level of education	11
		Section B: Medical and Visual Information	
12	Date of enrollment	Medical information retrieved from	12
	Family Information		
13	Mom's DOB	Date of or age at visual diagnosis	13
14	Dad's DOB	Primary dx in the right eye	14
15	Child lives with	Additional dx in the right eye	15
16	Language	Primary dx in the left eye	16
17	Educational levels of mom and dad	Additional dx in the left eye	17
	Medical Information		
18	Primary dx in right eye	Etiology of VI	18
19	Additional dx in right eye	If postnatal, is it NAT?	19

Table 33, continued

Old Form		New Form	
Item #	Description	Description	Item #
20	Primary dx in left eye	Glasses/contacts/prosthesis	20
21	Additional dx in left eye	Additional medical/health conditions	21
22	Atypical visual behaviors	Presence of additional developmental delays	22
23	Other VI conditions	Level of functional vision	23
24	Glasses/contacts/prosthesis	Level of overall developmental needs	24
25	Legally blind	Primary learning channel	25
		Section C: EI Service Information	
26	Visual acuity in right eye	Zip code	26
27	Visual acuity In left eye	Date of referral	27
28	Visual acuity in both	Date of enrollment	28
29	How was visual acuity determined	Family referral by	29
30	Awareness of	Who is providing services	30
31	Attention or fixation to	What is the frequency of service	31
32	Following or tracking	Where are services provided	32
33	Etiology of VI	Related services	33
		Section D: Program Exit Information	
34	Additional medical/health conditions	Date of exit	34
35	Hearing test	Reason for exit	35
	EI Service Information		
36	Family referred by	Program child is transitioning to	36
37	How services are provided	Receiving specialized VI services in new	37
38	Where are services provided		
39	Who is providing services		
40	Related services		
	Program Update		
41	Child's current status		
	Transitional Information		
42	Program child is transitioning to		
43	Receiving specialized VI services in new		
44	Date of exit		

APPENDIX C

INSTITUTIONAL REVIEW BOARD APPROVAL LETTER



UNIVERSITY OF
NORTHERN COLORADO

Institutional Review Board

DATE: January 25, 2017

TO: DeEtte Snyder
FROM: University of Northern Colorado (UNCO) IRB

PROJECT TITLE: [1015651-1] Trends in Identification and Service Provision for Young Children with Visual Impairments
SUBMISSION TYPE: New Project

ACTION: APPROVAL/VERIFICATION OF EXEMPT STATUS
DECISION DATE: January 25, 2017
EXPIRATION DATE: January 25, 2021

Thank you for your submission of New Project materials for this project. The University of Northern Colorado (UNCO) IRB approves this project and verifies its status as EXEMPT according to federal IRB regulations.

Thank you for a thorough and clear IRB application. Your materials and protocols are verified/ approved exempt and you may proceed with this research.

Best wishes with your study.

Sincerely,

Dr. Megan Stellino, UNC IRB Co-Chair

We will retain a copy of this correspondence within our records for a duration of 4 years.

If you have any questions, please contact Sherry May at 970-351-1910 or Sherry.May@unco.edu. Please include your project title and reference number in all correspondence with this committee.

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within University of Northern Colorado (UNCO) IRB's records.

APPENDIX D

BABIES COUNT DATA COLLECTION FORM

Babies Count Data Collection Form

Section Pre A: CHILD and FAMILY INFORMATION

1. Gender (Choose **only** one):
   - ☐ Male
   - ☐ Female

2. Date of Birth: Month______ Day______ Year______

3. Birth weight (Choose **only** one):
   - ☐ Weight in ____ (grams)
   - ☐ Weight in ____ (pounds)
   - ☐ Unknown

Section A CHILD and FAMILY INFORMATION

Information about the child:

4. Ethnicity of child (check **all** that apply):
   - ☐ Caucasian/White ☐ African American/Black
   - ☐ Native Alaskan/American Indian
   - ☐ Asian ☐ Hispanic/Latino
   - ☐ Pacific Islander
   - ☐ Middle Eastern/North African
   - ☐ Other_________ ☐ Unknown
   - ☐ Declined to Answer

5. Gestational age at birth (Choose **only** one):
   - ☐ Age in Weeks _____
   - ☐ Full Term - 38 weeks
   - ☐ Unknown

6. Is this child part of multiple births? (Choose **only** one):
   - ☐ No
   - ☐ Twins
   - ☐ Triplets
   - ☐ Other____________

Information about parents/guardians

7. Biological mother's age at the birth of child (Choose **only** one):
    - ☐ Age____
    - ☐ Unknown
    - ☐ Declined to answer

8. Biological father's age at the birth of child (Choose **only** one):
    - ☐ Age____
    - ☐ Unknown
    - ☐ Declined to answer

9. Child currently resides primarily with (check **all** persons currently living with child):

☐ Declined to answer

Mother	☐ Biological	☐ Foster	☐ Adoptive	☐ Step
2nd Mother	☐ Biological	☐ Foster	☐ Adoptive	☐ Step
Father	☐ Biological	☐ Foster	☐ Adoptive	☐ Step
2nd Father	☐ Biological	☐ Foster	☐ Adoptive	☐ Step
Grandmother	☐ Maternal	☐ Paternal		
Grandfather	☐ Maternal	☐ Paternal		
Other Adult	☐ Related	☐ Unrelated		
Siblings	☐ _________ (how many)			

10. Is English the primary language spoken in home? (Choose **only** one)
    - ☐ Yes
    - ☐ No
    - ☐ Declined to answer

11. Level of education completed by parent/guardian: (check **all** that apply):

Mother:	Father:
☐ Highest Grade Completed_____	☐ Highest Grade Completed_____
☐ High School Diploma or GED	☐ High School Diploma or GED
☐ Some College	☐ Some College
☐ Associate Degree	☐ Associate Degree
☐ Bachelor's Degree	☐ Bachelor's Degree
☐ Some Graduate Courses	☐ Some Graduate Courses
☐ Graduate Degree	☐ Graduate Degree
☐ Unknown	☐ Unknown
☐ Declined to answer	☐ Declined to answer

Section B: MEDICAL and VISUAL INFORMATION

Complete this section at both **entry** and **exit.**

12. The visual diagnosis information was obtained by (Choose **only** one):
    - ☐ Medical records
    - ☐ Parent report

13. Date of visual diagnosis **OR** age (in nearest whole month) at the time of diagnosis (Choose **only** one):

    - ☐ Month______ Day______ Year______
    - ☐ _____Age (in months)
    - ☐ Diagnosis is suspected and not yet officially diagnosed by a doctor.

14 – 17. **Visual diagnosis:**

	Left Eye		**Right Eye**	
	14. Primary Check only **one**	**15. Additional** Check **all** that apply	**16. Primary** Check only **one**	**17. Additional** Check **all** that apply
Albinism	☐	*	☐	*
Amblyopia	*	☐	*	☐
Aniridia	☐	*	☐	*
Anophthalmia	☐	*	☐	*
Aphakia	☐	☐	☐	☐
Cataracts (corrected and uncorrected)	☐	☐	☐	☐
Chorioretinitis	☐	☐	☐	☐
Coloboma	☐	☐	☐	☐
Corneal Defects/Peter's Anomaly	☐	*	☐	*
Cortical Visual Impairment (CVI)	☐	☐	☐	☐
Delayed Visual Maturation	☐	☐	☐	☐
Enucleation	☐	*	☐	*
Familial Exudative Vitreoretinopathy (FEVR)	☐	*	☐	*
Glaucoma	☐	☐	☐	☐
Hemianopsia/Hemianopia	☐	☐	☐	☐
Leber's Congenital Amaurosis	☐	*	☐	*
Microphthalmia	☐	☐	☐	☐
Nystagmus, Congenital Motor	☐	☐	☐	☐
Oculomotor Apraxia & Eye Movement Disorders	☐	☐	☐	☐
Optic Atrophy	☐	☐	☐	☐
Optic Glioma	☐	☐	☐	☐
Optic Nerve Hypoplasia (ONH)	☐	*	☐	*
Persistent Hyperplasia of the Primary Vitreus (PHPV)	☐	☐	☐	☐
Ptosis	☐	☐	☐	☐

Refractive Errors	*	☐	*	☐
Retinal Disorder-non specific	☐	☐	☐	☐
Retinitis Pigmentosa (RP)	☐	*	☐	*
Retinoblastoma	☐	*	☐	*
Retinopathy of Prematurity (ROP)	☐	☐	☐	☐
Rod/Cone Dystrophies	☐	*	☐	*
Strabismus	*	☐	*	☐
Other: ____________________	☐	☐	☐	☐
Unknown and examined/tested by a doctor	☐	☐	☐	☐
Unknown, NOT examined or tested by doctor	☐	☐	☐	☐
no additional diagnosis	*	☐	*	☐

18. Occurrence of etiology of documented or suspected visual impairment (Choose **only** one):

☐ Prenatal- Before birth
☐ Perinatal- During birth or immediately after birth
☐ Postnatal- After birth or after the child leaves the hospital
☐ Unknown

19. Is the visual impairment due to a **non-accidental trauma (NAT),** also including Shaken Baby Syndrome? (Choose **only** one):
☐ Yes
☐ No
☐ Unknown

20. The child currently has one or more of the following: (check **all** that apply):
☐ Glasses
☐ Contact Lenses
☐ Prosthesis (one eye or both)
☐ None of the above

21. Additional medical and health conditions (check **all** that apply):
☐ Allergies
☐ Cancer
☐ Endocrine Disorder
☐ Feeding Problems
☐ Heart Disorder
☐ Respiratory Problems
☐ Autism Spectrum Disorder
☐ Cerebral Palsy
☐ Deaf or Hard of Hearing
☐ Orthopedic Impairment
☐ Seizure Disorder/Infantile Spasms
☐ Technology Dependent
☐ Other Medical or Health Conditions: ______________________
☐ None

22. Presence of additional developmental delays (check **all** that apply):
    - ☐ Cognitive Delays
    - ☐ Fine Motor Delays
    - ☐ Social Skills Delays
    - ☐ None or not yet determined
    - ☐ Language Delays
    - ☐ Gross Motor Delays
    - ☐ Adaptive Skills Delays

Summary of child:

23. This child's functional vision can best be described as: (choose **only** one)
    - ☐ Normal or near normal visual functioning
    - ☐ Low Vision
    - ☐ Meets the definition of blindness
    - ☐ Functions at the definition of blindness

24. This child's overall developmental needs can best be described as: (choose **only** one)
    - ☐ Typical development
    - ☐ Mild to moderate support needs
    - ☐ Intensive support needs

25. This child's primary learning channel can best be described as: (choose **only** one)
    - ☐ Visual
    - ☐ Tactual
    - ☐ Auditory
    - ☐ Unknown

Section C: EARLY INTERVENTION SERVICE INFORMATION

Complete this section at both entry and exit.

26. Postal zip code of primary residence: ____________

27. Date of **referral** to program for specialized vision services:
M _____ D_____ Y_____

28. Date of **enrollment** to program for specialized vision services:
M _____ D _____ Y _____

29. Family referred for specialized vision services by (choose **only** one):
    - ☐ Medical Provider (indicate specialty) __________________________
    - ☐ Child Find / Public Agency
    - ☐ Early Intervention Program
    - ☐ Family/Friend
    - ☐ Other (specify) ____
    - ☐ Unknown

30. **Who** is/was providing specialized vision services to the child and family? (Check **all** that apply):

☐ State licensed teacher of students with visual impairments
☐ Other licensed professional employed and trained by specialized program for VI
☐ Certified Orientation & Mobility Specialist
☐ Deaf/Blind Specialist
☐ Other (specify) ___________________
☐ No ongoing specialized VI services provided to child and family

31. **What** frequency of ongoing specialized vision services will be/were provided to the child and family? (Choose **ONLY** one):

☐ Weekly specialized VI services to family and team
☐ Bi-weekly specialized VI services to family and team
☐ Monthly specialized VI services to family and team
☐ Quarterly specialized VI services to family and team
☐ Annual specialized VI services to family and team
☐ Consultation specialized VI services only as needed when requested
☐ One time evaluation only
☐ Other (Specify): ___________

32. **Where** are/were specialized vision services provided? (Check **all** that apply):

☐ Home
☐ Family/Home Daycare(or other community environments)
☐ Specialized VI/EI Program
☐ Early Intervention Center
☐ Day Care Center
☐ Other (specify) ____________________________
☐ No ongoing specialized VI services provided to child and family
☐ Hospital
☐ Residential Care Facility
☐ Medical visit with family

33. Which additional early Intervention service(s) does/did the child and family receive? (Check **all** that apply):

☐ Developmental Special Instruction
☐ Occupational Therapy
☐ Physical Therapy
☐ Speech/Language Pathology Services
☐ Social Work Services
☐ Psychological Services
☐ D/HH Services/Audiology
☐ Other (specify) ______
☐ No other services
☐ Unknown

Section D: PROGRAM EXIT INFORMATION

Complete this section at **EXIT only**.

Transitional Information:

34. Date of **exit** from the program for specialized VI services:
M _____ D_____ Y_____

35. Reason child exited specialized VI services (Choose **only** one):
- ☐ Turned three years of age
- ☐ Moved
- ☐ No longer in need of specialized VI services
- ☐ Parent declined services
- ☐ Unable to contact family
- ☐ Deceased
- ☐ Other (specify) ____

36. If child exited from program at age 3, indicate type of program child transitioned to: (Check **all** that apply.) (Only if question 35 has turned 3 checked)
- ☐ Community Preschool Classroom, including Head Start
- ☐ Day Care Setting
- ☐ Public School Special Education Preschool Classroom
- ☐ Public School Special Education Preschool Classroom for Students with VI
- ☐ Day-School/Preschool for Students with VI in a Specialized VI Program
- ☐ Home-Based Special Education Services
- ☐ Home School
- ☐ Pediatric Health Care Facility
- ☐ Unknown
- ☐ None
- ☐ Other (specify) ____

37. Will specialized VI services be provided to this child in new setting? (Choose **only** one):
- ☐ Yes
- ☐ No
- ☐ Unknown

APPENDIX E

BABIES COUNT SURVEY CODES

Babies Count Survey Codes

Table 34

Babies Count Survey Codes

Survey #	Survey item/study variable	Code
	Child Information	
1	Gender	
	Male	0
	Female	1
2	Date of birth (not included; used to calculate ages of events)	
3	Birth weight (continuous)	
4a	Ethnicity of child	
	Caucasian/White	0
	Hispanic/Latino	1
	African American/Black	2
	Middle Eastern/North African	3
	Asian	4
	Unknown	5
	Native American	6
	Pacific Islander	7
4b	Number of ethnic groups	
	Unknown ethnicity	0
	One ethnic group	1
	Two ethnic groups	2
	Three or more ethnic groups	3
5	Gestational age at birth	
	Full term to 38 weeks	0

Table 34, continued

Survey #	Survey item/study variable	Code
	37 to 33 weeks	1
	32-28 weeks	2
	Less than 28 weeks	3
	Unknown	4
6	Is this child part of a multiple birth?	
	Single	0
	Twin	1
	Triplet	2
	Other	3
	Family Information	
7	Biological mother's age at the birth of child (continuous)	
	Biological mother's age- grouped	
	Unknown	0
	15-19 years old (teens)	1
	20-29 years old (20s)	2
	30-39 years old (30s)	3
	40-49 years old (40s)	4
8	Biological fathers age at the birth of child (continuous)	
	Biological father's age- grouped	
	Unknown	0
	16-19 years old (teens)	1
	20-29 years old (20s)	2
	30-39 years old (30s)	3
	40-49 years old (40s)	4
	50 or older	5
9a	Child resides primarily/child's caregiver(s)	
	Biological mom and dad	0

Table 34, continued

Survey #	Survey item/study variable	Code
	Single biological parent	1
	Other adult	2
	Foster family/adoptive	3
	Unknown	4
9b	How many siblings?	
	None	0
	One sibling	1
	Two siblings	2
	Three or more siblings	3
10	Is English the primary language at home?	
	Yes/English	0
	No/not English	1
	Unknown/declined to answer	2
11a	Mother’s level of education	
	Did not graduate high school	0
	High school diploma or equivalent	1
	Some college/aa degree	2
	Bachelor’s degree	3
	Graduate degree	4
	Unknown/declined to answer	5
11b	Father’s level of education	
	Did not graduate high school	0
	High school diploma or equivalent	1
	Some college/Associate’s degree	2
	Bachelor’s degree	3
	Graduate degree	4
	Unknown/declined to answer	5

Table 34, continued

Survey #	Survey item/study variable	Code
	Medical and visual information	
12	The visual diagnosis was obtained by: (not included in analysis)	
	medical records	0
	parent report	1
13	Age of diagnosis (continuous)	
14	Right eye primary condition	
	Cortical visual impairment (CVI/DVM)	0
	Optic nerve hypoplasia (ONH)	1
	Nystagmus	2
	Retinopathy of prematurity (ROP)	3
	Albinism	4
	Leber's congenital amaurosis (LCA)	5
	Cataracts	6
	Glaucoma	7
	Aniridia	8
	Microphthalmia/anophthalmia	9
	Coloboma	10
	Corneal defects/disorders (i.e. Peter's anomaly)	11
	Retinal defects/disorders	12
	Retinoblastoma	13
	Ocular motor apraxia (OMA)	14
	Optic atrophy	15
	Familial exudative vitreoretinopathy (FEVR)	16
	Persistent hyperplasic primary vitreous (PHPV)	17

Table 34, continued

Survey #	Survey item/study variable	Code
	Retinitis pigmentosa (RP)	18
	Hemianopia/field loss	19
	Nerve palsy/ptosis	20
	Unknown/none	21
	Strabismus	22
	Goldenhar syndrome	23
	Choroidal hemangioma	24
	Aniscoria	25
	High refraction	26
	Right eye primary-grouped	
	Cortical visual impairment (CVI/DVM)	0
	Optic nerve hypoplasia (ONH)	1
	Retinopathy of prematurity (ROP)	2
	Albinism	3
	Structural disorder	4
	Retinal disorder	5
	Other/Miscellaneous	6
	Unknown or none	7
15a	Right eye additional/secondary eye condition	
	None	0
	Nystagmus	1
	Strabismus	2
	Amblyopia	3
	Refractive errors	4
	Ptosis	5
	Optic atrophy	6
	Cataracts/aphakia	7

Table 34, continued

Survey #	Survey item/study variable	Code
	Glaucoma	8
	Cortical visual impairment (CVI/DVM)	9
	Persistent hyperplastic primary vitreous (PHPV)	10
	Coloboma	11
	Microphthalmia	12
	Hemianopia	13
	Retinopathy of prematurity (ROP)	14
	Ocular motor apraxia (OMA)	15
	Retinal defect/disorder	16
	Corneal defect/disorder	17
	Vitreous hemorrhage	18
	Number of right eye additional/secondary	
15b	*None*	0
	One additional	1
	Two additional	2
	Three additional	3
	Four additional	4
	Five additional	5
16	Left eye primary condition	
	Cortical visual impairment (CVI/DVM)	0
	Optic nerve hypoplasia (ONH)	1
	Nystagmus	2
	Retinopathy of prematurity (ROP)	3
	Albinism	4
	Leber's congenital amaurosis (LCA)	5
	Cataracts	6

Table 34, continued

Survey #	Survey item/study variable	Code
	Glaucoma	7
	Aniridia	8
	Microphthalmia/anophthalmia	9
	Coloboma	10
	Corneal defects/disorders (i.e. Peter's anomaly)	11
	Retinal defects/disorders	12
	Retinoblastoma	13
	Ocular motor apraxia (OMA)	14
	Optic atrophy	15
	Familial exudative vitreoretinopathy (FEVR)	16
	Persistent hyperplasic primary vitreous (PHPV)	17
	Retinitis pigmentosa (RP)	18
	Hemianopia/field loss	19
	Nerve palsy/ptosis	20
	Unknown/none	21
	Strabismus	22
	Goldenhar syndrome	23
	Choroidal hemangioma	24
	Aniscoria	25
	High refraction	26
	Left eye primary-grouped	
	Cortical visual impairment (CVI/DVM)	0
	Optic nerve hypoplasia (ONH)	1
	Retinopathy of prematurity (ROP)	2
	Albinism	3

Table 34, continued

Survey #	Survey item/study variable	Code
	Structural disorder	4
	Retinal disorder	5
	Other/miscellaneous	6
	Unknown or none	7
17a	Left eye additional/secondary eye condition	
	None	0
	Nystagmus	1
	Strabismus	2
	Amblyopia	3
	Refractive errors	4
	Ptosis	5
	Optic atrophy	6
	Cataracts/aphakia	7
	Glaucoma	8
	Cortical visual impairment (CVI/DVM)	9
	Persistent hyperplastic primary vitreous (PHPV)	10
	Coloboma	11
	Microphthalmia	12
	Hemianopia	13
	Retinopathy of prematurity (ROP)	14
	Ocular motor apraxia (OMA)	15
	Retinal defect/disorder	16
	Corneal defect/disorder	17
	Vitreous hemorrhage	18
17b	Number of right eye additional/secondary	
	None	0

Table 34, continued

Survey #	Survey item/study variable	Code
	One additional	1
	Two additional	2
	Three additional	3
	Four additional	4
	Five additional	5
18	Occurrence of etiology	
	Prenatal	0
	Perinatal	1
	Postnatal	2
	Unknown	3
19	Visual impairment due to non-accidental trauma (NAT)	
	No	0
	Yes	1
	Unknown	2
20	Visual optics use	
	None	0
	Glasses	1
	Glasses and contact lens	2
	Prosthesis	3
	Contacts	4
21a	Additional medical and health conditions	
	None	0
	Autism spectrum disorder	1
	Cerebral palsy/orthopedic impairment	2
	Endocrine disorder	3
	Deaf/hard Of hearing (DHH)	4
	Feeding Problems	5

Table 34, continued

Survey #	Survey item/study variable	Code
	Seizure disorder/infantile spasms	6
	Chromosomal condition	7
	Mitochondrial disease	8
	Cancer	9
	Heart disorder	10
	Technology dependent	11
	Sleep issue	12
	Gastro-intestinal/reflux issues	13
	Congenital brain abnormalities	14
	Spina bifida	15
	Born with addiction	16
	Respiratory problems	17
	Allergies	18
	Hereditary syndrome	19
	Acquired brain condition	20
	Craniofacial (Moebius syndrome)	21
	Arachnoid cyst in brain	22
	Genetic disorder	23
	Viral sepsis infection	24
	Additional medical and health conditions-grouped	
	None	0
	Neurological	1
	Global syndromes	2
	Endocrine	3
	Deaf/hard of hearing (DHH)	4
	Feeding issues	5
	Other/miscellaneous	6

Table 34, continued

Survey #	Survey item/study variable	Code
21b	Number of medical/health conditions	
	None	0
	One condition	1
	Two conditions	2
	Three conditions	3
	Four conditions	4
	Five conditions	5
	Six or more conditions	6
22a	Presence of developmental delays per domain	
	None	0
	Cognitive	1
	Language	2
	Social	3
	Fine motor	4
	Gross motor	5
	Adaptive	6
22b	Number of developmentally delayed domains	
	None	0
	Delay in one domain	1
	Delay in two domains	2
	Delay in three domains	3
	Delays in four domains	4
	Delays in five domains	5
	Delays in all six domains	6
23	Level of visual function	
	Meets the definition of blindness (MDB)	0
	Functions at the definition of blindness (FDB)	1

Table 34, continued

Survey #	Survey item/study variable	Code
	Low vision	2
	Normal or near normal visual functioning	3
24	Overall developmental support needs	
	Typical support needs	0
	Mild to moderate support needs	1
	Profound/intensive support needs	2
25	Primary learning channel	
	Visual	0
	Tactual	1
	Auditory	2
	Unknown	3
	Early Intervention services	
26	State/zip code	
	California	0
	Maryland	1
	New Mexico	2
	Utah	3
	Washington	4
13a	Age at diagnosis (continuous)	
13b	Months between diagnosis and referral (continuous)	
27a	Age at referral (continuous)	
27b	Days between referral and enrollment (continuous)	
28a	Age at enrollment (continuous)	
29	Referral source	
	Early intervention program/Child Find	0
	Medical professional	1
	Family	2

Table 34, continued

Survey #	Survey item/study variable	Code
	Unknown	3
	Other	4
30	Specialized visual impairment service provider	
	State certified teacher of the visually impaired (CTVI)	0
	Other trained professional at VI Agency	1
	State certified orientation & mobility specialist (O&M)	2
	Deaf-Blind (DB) specialist	3
	CTVI & O&M team	4
	CTVI & DB specialist team	5
	CTVI, O&M, and DB specialist team	6
	Certified vision rehabilitation therapist (CVRT)	7
31	Frequency of specialized visual impairment service	
	Weekly	0
	Bi-weekly	1
	Monthly	2
	Quarterly	3
	Other	4
	Bi-monthly	5
	Annual	6
	Consultation as needed	7
32	Location of specialized visual impairment service	
	Home	0
	Program/agency for visually impaired	1
	Natural environment	2

Table 34, continued

Survey #	Survey item/study variable	Code
	General early intervention program/agency	3
	Residential care facility	4
	Home and other	5
33a	Other early intervention services	
	None	0
	Special instruction	1
	Occupational therapy	2
	Physical therapy	3
	Speech/language services	4
	Deaf/hard of hearing services	5
	Other	6
	• *Social work*	
	• *Psychological services*	
	• *Nursing services*	
	• *Applied behavior analysis*	
	• *Feeding & nutritional services*	
	• *Other/non-IDEA activities*	
	• *Assistive technology*	
33b	Number of additional early intervention (EI) services	
	None	0
	One additional EI service	1
	Two additional EI services	2
	Three additional EI services	3
	Four or more additional EI services	4

APPENDIX F

BABIES COUNT DESCRIPTIVE TOTALS AS OF JUNE 2017

Babies Count Descriptive Totals as of June 2017

Table 35

Descriptive Statistics for Child Characteristics-Categorical Variables

Child characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Gender												
Male	308	52.4	50	48.0	36	51.4	88	50.9	81	59.6	53	50.5
Female	280	47.6	54	52.0	34	48.6	85	49.1	55	40.4	52	49.5
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Gestational age												
Full Term	332	59.5	67	65.0	35	55.5	93	56.0	72	58.0	65	63.7
37 to 33 weeks	129	23.1	24	23.3	16	25.4	37	22.3	26	21.0	26	25.5
32 to 28 weeks	44	7.9	4	3.9	3	4.8	24	14.5	11	8.9	2	2.0
Less than 28 weeks	53	9.5	8	7.8	9	14.3	12	7.2	15	12.1	9	8.8
Total	558	100.0	103	100.0	63	100.0	166	100.0	124	100.0	102	100.0
Missing/unreported/unknown	30	5.1	1	1.0	7	10.0	7	4.0	12	8.8	3	2.8
Multiple births												
Single	557	94.7	100	96	67	95.7	164	94.8	124	91.2	102	97.1
Twins	30	5.1	4	4	3	4.3	8	4.6	12	8.8	3	2.9
Triplets	1	0.2	-	-	-	-	1	.6	-	-	-	-
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Both eyes primary- grouped												
CVI/DVM	171	29.1										
ONH	64	10.9										
ROP	50	8.5										
Structural	38	6.4										
Retinal disorder	24	4.1										

Table 35, continued

Child characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Albinism	18	3.1										
Other	132	22.4										
Unknown	91	15.5										
Total	588	100.0										
Right eye primary												
Unknown/undiagnosed	99	16.8	27	26.0	4	5.7	27	15.6	35	25.7	8	7.5
CVI/DVM	171	29.1	19	18.3	19	27.2	68	39.3	26	19.1	39	37.0
ONH	63	10.7	6	5.8	8	11.4	16	9.3	12	9.0	20	19.0
ROP	50	8.5	4	3.8	10	14.3	15	8.7	13	9.6	8	7.6
Albinism	18	3.1	3	2.9	5	7.2	3	1.7	5	3.7	2	1.9
Structural	34	5.8	5	4.8	6	8.6	6	3.5	10	7.4	7	6.6
Aniridia	*6*	*1.0*	-	-	*1*	*1.4*	*2*	*1.1*	*1*	*0.7*	*2*	*1.9*
Microphthalmia/anophthalmia	*10*	*1.7*	*1*	*1.0*	*3*	*4.3*	*1*	*0.6*	*2*	*1.5*	*3*	*2.9*
Coloboma	*12*	*2.0*	*3*	*2.9*	*1*	*1.4*	*2*	*1.1*	*5*	*3.7*	*1*	*1.0*
Corneal defect/disorder	*5*	*0.9*	*1*	*1.0*	*1*	*1.4*	*1*	*0.6*	*1*	*0.7*	*1*	*1.0*
Goldenhar syndrome	*1*	*0.2*	-	-	-	-	-	-	*1*	*0.7*	-	-
Retinal disorders	24	4.1	9	3.9	3	4.3	7	4.0	1	0.7	4	3.8
LCA	*4*	*0.7*	*2*	*1.9*	-	-	-	-	*1*	*0.7*	*1*	*1.0*
Retinal defect/disorder	*14*	*2.4*	*4*	*3.9*	*1*	*1.4*	*6*	*3.5*	-	-	*3*	*2.9*
Retinoblastoma	*3*	*0.5*	*1*	*1.0*	*2*	*2.9*	-	-	-	-	-	-
FEVR	*3*	*0.5*	*2*	*1.9*	-	-	*1*	*0.6*	-	-	-	-
Other	129	21.9	31	29.8	15	21.4	31	17.9	35	25.7	17	16.2
Nystagmus	*32*	*5.4*	*9*	*8.7*	*3*	*4.3*	*10*	*5.8*	*8*	*6.0*	*2*	*1.9*
Strabismus	*26*	*4.4*	*7*	*6.75*	*2*	*2.9*	*3*	*1.7*	*13*	*9.6*	*1*	*1.0*
Cataracts	*12*	*2.0*	*3*	*1.9*	*1*	*1.4*	*4*	*2.3*	*2*	*1.5*	*2*	*1.9*
Glaucoma	*9*	*1.5*	-	-	*1*	*1.4*	*1*	*0.6*	*2*	*0.7*	*5*	*4.7*
OMA	*8*	*1.4*	*2*	*1.9*	-	-	*2*	*1.1*	*1*	*0.7*	*3*	*2.9*

Table 35, continued

Child characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Optic atrophy	*16*	*2.7*	*2*	*1.9*	*1*	*1.4*	*6*	*3.5*	*4*	*2.9*	*3*	*2.9*
PHPV	*1*	*0.2*	-	-	*1*	*1.4*	-	-	-	-	-	-
Hemianopsia/field loss	*6*	*1.0*	*3*	*2.9*	*1*	*1.4*	-	-	*1*	*0.7*	*1*	*1*
Nerve palsy/ptosis	*6*	*1.0*	*1*	*1.0*	*2*	*2.9*	*1*	*0.6*	*2*	*1.5*	-	-
Choroidal hemangioma	*1*	*0.2*	-	-	-	-	-	-	*1*	*0.7*	-	-
Aniscoria	*1*	*0.2*	-	-	-	-	-	-	*1*	*0.7*	-	-
High refraction	*11*	*1.9*	*4*	*3.8*	*3*	*4.3*	*4*	*2.3*	-	-	-	-
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Right eye additional												
None	302	51.4	63	60.6	36	51.4	81	46.8	77	56.6	45	42.9
Refractive error	88	15.0	19	18.3	1	1.4	32	18.5	24	17.6	12	11.4
Nystagmus	87	14.8	12	11.5	20	28.6	23	13.3	14	10.3	18	17.1
Strabismus	78	13.3	9	8.7	6	8.6	25	14.5	16	11.8	22	21.0
Amblyopia	37	6.3	6	5.8	3	4.3	13	7.5	10	7.4	5	4.8
CVI/DVM	23	3.9	7	6.7	-	-	6	3.5	4	2.9	6	5.7
Optic atrophy	22	3.7	3	2.9	-	-	14	8.1	3	2.2	2	1.9
Ptosis	14	2.4	3	2.9	-	-	6	3.5	2	1.5	3	2.9
Cataracts	8	1.4	-	-	1	1.4	1	0.6	-	-	6	5.7
Coloboma	7	1.2	-	-	2	2.9	-	-	1	0.7	3	2.9
Glaucoma	6	1.0	-	-	1	1.4	-	-	2	1.0	3	2.9
OMA	4	0.7	2	1.9	-	-	-	-	1	0.7	1	1.0
Microphthalmia	3	0.5	-	-	1	1.4	-	-	1	0.7	1	1.0
PHPV	2	0.3	-	-	-	-	1	0.6	-	-	2	1.9
Hemianopsia	2	0.3	-	-	-	-	-	-	-	-	2	1.9
ROP	2	0.3	-	-	-	-	1	0.6	-	-	1	1.0
Retinal defect/disorder	1	0.2	-	-	1	1.4	-	-	-	-	-	-
Corneal defect/disorder	1	0.2	-	-	-	-	1	0.6	-	-	-	-
Vitreous hemorrhage	1	0.2	-	-	-	-	1	0.6	-	-	-	-

Table 35, continued

Child characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Total	688	-	124	-	72	-	205	-	155	-	132	-
Number of right eye additional												
None	302	51.4	63	60.6	36	51.4	81	46.8	77	56.6	45	42.8
One additional	218	37.1	30	28.8	32	45.7	69	39.9	45	33.1	42	40.0
Two additional	47	7.0	5	4.8	2	2.9	16	9.2	9	6.6	15	14.3
Three additional	15	2.5	4	3.8	-	-	5	2.9	5	3.7	1	1.0
Four additional	3	0.5	1	1.0	-	-	2	1.2	-	-	-	-
Five additional	3	0.5	1	1.0	-	-	-	-	-	-	2	1.9
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Left eye primary												
Unknown/undiagnosed	106	18.0	27	26.0	5	7.2	29	16.8	37	27.0	8	7.6
CVI/DVM	172	29.3	19	18.3	19	27.2	68	39.3	27	19.8	39	37.0
ONH	61	10.4	6	5.8	7	10.0	16	9.3	13	9.5	19	18.0
ROP	50	8.5	4	3.8	10	14.3	15	8.7	13	9.5	8	7.6
Albinism	18	3.1	3	2.9	5	7.2	3	1.7	5	3.6	2	1.9
Structural	30	5.1	5	4.8	7	10.0	5	2.9	7	5.2	6	5.7
Aniridia	*6*	*1.0*	-	-	*1*	*1.4*	*2*	*1.1*	*1*	*0.7*	*2*	*1.9*
Microphthalmia/anophthalmia	*12*	*2.0*	*1*	*1.0*	*4*	*5.7*	*2*	*1.1*	*2*	*1.5*	*3*	*2.9*
Coloboma	*7*	*1.2*	*3*	*2.9*	*1*	*1.4*	*1*	*0.6*	*2*	*1.5*	-	-
Corneal defect/disorder	*5*	*0.9*	*1*	*1.0*	*1*	*1.4*	-	-	*2*	*1.5*	*1*	*1.0*
Retinal	22	3.7	8	7.7	2	2.9	6	3.5	1	0.7	5	4.8
LCA	*4*	*0.7*	*2*	*1.9*	-	-	-	-	*1*	*0.7*	*1*	*1.0*
Retinal defect/disorder	*13*	*2.2*	*4*	*3.8*	-	-	*5*	*2.9*	-	-	*4*	*3.8*
Retinoblastoma	*2*	*0.3*	-	-	*2*	*2.9*	-	-	-	-	-	-
FEVR	*3*	*0.5*	*2*	*1.9*	-	-	*1*	*0.6*	-	-	-	-
Other	129	21.9	32	30.8	15	21.4	31	17.9	33	24.3	18	17.2

Table 35, continued

Child Characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Nystagmus	*34*	*5.8*	*9*	*8.7*	*4*	*5.7*	*10*	*5.8*	*9*	*6.6*	*2*	*1.9*
Strabismus	*25*	*4.2*	*7*	*6.7*	*1*	*1.4*	*3*	*1.7*	*12*	*8.8*	*2*	*1.9*
Cataracts	*13*	*2.2*	*2*	*1.9*	*2*	*2.9*	*4*	*2.3*	*3*	*2.2*	*2*	*1.9*
Glaucoma	*8*	*1.4*	-	-	*1*	*1.4*	*1*	*0.6*	*1*	*0.5*	*5*	*4.8*
OMA	*8*	*1.4*	*2*	*1.9*	-	-	*2*	*1.1*	*1*	*1.5*	*3*	*2.9*
Optic atrophy	*15*	*2.5*	*2*	*1.9*	*1*	*1.4*	*6*	*3.5*	*3*	*2.2*	*3*	*2.9*
PHPV	*1*	*0.2*	-	-	*1*	*1.4*	-	-	-	-	-	-
Hemianopsia/field loss	*6*	*1.0*	*3*	*2.9*	*1*	*1.4*	-	-	*1*	*0.7*	*1*	*1.0*
Nerve palsy/ptosis	*6*	*1.0*	*2*	*1.9*	*1*	*1.4*	*1*	*0.6*	*2*	*1.5*	-	-
Aniscoria	*1*	*0.2*	-	-	-	-	-	-	*1*	*0.7*	-	-
High refraction	*12*	*2.0*	*5*	*4.8*	*3*	*4.3*	*4*	*2.3*	-	-	-	-
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Left Eye Additional												
None	321	54.6	62	59.6	37	52.9	89	51.4	84	61.8	49	46.7
Nystagmus	86	14.6	12	11.5	20	28.6	22	12.7	14	10.3	18	17.1
Refractive error	80	13.6	19	18.3	1	1.4	32	18.5	18	13.2	10	9.5
Strabismus	72	12.2	11	10.6	5	7.1	21	12.1	16	11.8	19	18.1
CVI/DVM	23	3.9	7	6.7	-	-	6	3.5	4	2.9	6	5.7
Optic atrophy	20	3.4	3	2.9	-	-	13	7.5	3	2.2	1	1.0
Amblyopia	20	3.4	3	2.9	1	1.4	9	5.2	4	2.9	3	2.9
Ptosis	15	2.6	3	2.9	-	-	7	4.0	2	1.5	3	2.9
Cataracts	9	1.5	-	-	3	4.3	1	0.6	1	0.7	4	3.8
Coloboma	5	0.9	-	-	1	1.4	-	-	2	1.5	2	1.9
Glaucoma	5	0.9	-	-	-	-	1	0.6	-	-	4	3.8
Microphthalmia	5	0.9	-	-	1	1.4	1	0.6	1	0.7	2	1.9
OMA	3	0.5	2	1.9	-	-	-	-	-	-	1	1.0
Hemianopsia	3	0.5	-	-	-	-	-	-	1	0.7	2	1.9
ROP	2	0.3	-	-	-	-	1	0.6	-	-	1	1.0

Table 35, continued

Child characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Retinal defect/disorder	1	0.2	-	-	1	1.4	-	-	-	-	-	-
PHPV	1	0.2	-	-	-	-	-	-	-	-	1	1.0
Vitreous hemorrhage	1	0.2	-	-	-	-	1	0.6	-	-	-	-
Total	672		122		70		204		150		126	
Number of left eye additional												
None	321	54.6	62	59.6	37	52.9	89	51.4	84	61.8	49	46.7
One additional	205	34.9	31	29.8	33	47.1	60	34.7	40	29.4	41	39.0
Two additional	45	7.6	6	5.8	-	-	18	10.4	10	7.3	11	10.5
Three additional	13	2.2	4	3.8	-	-	5	2.9	2	1.5	2	1.9
Four additional	3	0.5	-	-	-	-	1	0.6	-	-	2	1.9
Five additional	1	0.2	1	1.0	-	-	-	-	-	-	-	-
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Etiology												
Prenatal	232	53.7	38	64.4	34	54.8	71	56.0	44	49.4	45	47.4
Perinatal	87	20.1	8	13.6	11	17.7	28	22.0	15	16.9	25	26.3
Postnatal	113	26.2	13	22.0	17	27.5	28	22.0	30	33.7	25	26.3
Total	432	100.0	59	100.0	62	100.0	127	100.0	89	100.0	95	100.0
Missing/unreported/unknown	156	26.5	45	43.3	8	11.4	46	26.6	47	34.6	10	9.5
Non-accidental trauma (NAT)												
Not an NAT	555	95.5	95	93.1	69	98.6	162	94.7	129	96.3	100	96.1
NAT	26	4.5	7	6.9	1	1.4	9	5.3	5	3.7	4	3.9
Total	581	100.0	102	100.0	70	100.0	171	100.0	134	100.0	104	100.0
Missing/unreported/unknown	7	1.2	2	1.9	-	-	2	1.2	2	1.5	1	1
Visual Optics												
None	408	69.4	69	66.4	56	80.0	121	69.9	88	64.7	74	70.5

Table 35, continued

Child characteristic	All		CA		MD		NM		UT		WA	
	n	%	n	%	n	%	n	%	n	%	n	%
Glasses	170	28.9	33	31.7	11	15.7	51	29.5	46	33.8	29	27.6
Glasses and contacts	3	0.5	-	-	2	2.9	1	0.6	-	-	2	1.9
Prosthesis	4	0.7	-	-	-	-	-	-	2	1.5	-	-
Contacts	3	0.5	2	1.9	1	1.4	-	-	-	-	-	-
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Other medical conditions												
None	185	31.5	33	31.7	25	35.7	62	35.8	39	23.9	26	24.7
Endocrine	38	6.5	5	4.8	3	4.3	10	5.8	5	3.7	15	14.3
Deaf/hard of hearing	43	7.3	9	8.7	4	5.7	9	5.2	11	8.1	10	7.4
Feeding issues	193	32.8	31	29.8	18	25.7	54	31.2	50	36.8	40	38.1
Neurological	338	57.5	53	51.0	35	50.0	91	52.6	92	67.6	67	63.8
CP/OI	*134*	*22.8*	*20*	*19.2*	*12*	*17.1*	*39*	*22.5*	*36*	*26.5*	*27*	*25.7*
Seizures	*133*	*22.6*	*24*	*23.1*	*13*	*18.6*	*31*	*17.9*	*32*	*23.6*	*33*	*31.4*
Congenital brain abnormality	*34*	*5.8*	*6*	*5.8*	*6*	*8.6*	*10*	*5.8*	*8*	*5.9*	*4*	*3.8*
Acquired brain abnormality	*29*	*4.9*	*3*	*2.9*	*4*	*5.7*	*9*	*5.2*	*13*	*9.6*	-	-
ASD	*7*	*1.2*	-	-	-	-	*2*	*1.2*	*3*	*2.2*	*2*	*1.9*
Spina bifida	*1*	*0.2*	-	-	-	-	-	-	-	-	*1*	*1.0*
Global syndromes	57	9.7	15	14.4	6	8.6	22	12.7	13	9.6	1	1.0
Chromosomal disorder	*33*	*5.6*	*7*	*6.7*	*2*	*2.9*	*15*	*8.7*	*8*	*5.9*	*1*	*1.0*
Mitochondrial	*2*	*0.3*	-	-	-	-	*2*	*1.2*	-	-	-	
Hereditary syndrome	*1*	*0.2*	*1*	*1.0*	-	-	-	-	-	-	-	-
Cranio-facial disorder	*11*	*1.9*	*3*	*2.9*	*2*	*2.9*	*4*	*2.3*	*2*	*1.5*	-	-
Metabolic disorder	*2*	*0.3*	-	-	-	-	-	-	*2*	*1.5*	-	-
Genetic disorder	*8*	*1.4*	*4*	*3.8*	*2*	*2.9*	*1*	*0.6*	*1*	*0.7*	-	-
Other	234	39.8	34	32.7	18	25.7	76	43.9	58	42.6	48	45.7
Cancer	*6*	*1.0*	-	-	*2*	*2.5*	*3*	*1.7*	*1*	*0.7*	-	-
Heart disorder	*51*	*8.7*	*6*	*5.8*	*4*	*5.7*	*19*	*11.0*	*12*	*8.8*	*10*	*9.5*

Table 35, continued

Child characteristic	All		CA		MD		NM		UT		WA	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Tech dependent	*36*	*6.1*	*9*	*8.7*	-	-	*17*	*9.8*	*7*	*5.1*	*3*	*2.9*
Sleep issues	*2*	*0.3*	-	-	-	-	*1*	*0.6*	*1*	*0.7*	-	-
GERD/reflux	*4*	*0.7*	-	-	-	-	*1*	*0.6*	*1*	*0.7*	*2*	*1.9*
Born with addiction	*6*	*1.0*	*1*	*1.0*	-	-	*3*	*1.7*	-	-	*2*	*1.9*
Respiratory problems	*102*	*17.3*	*13*	*12.5*	*9*	*12.9*	*26*	*15.0*	*27*	*19.9*	*27*	*25.7*
Allergies	*26*	*4.4*	*4*	*3.8*	*3*	*4.3*	*6*	*3.5*	*9*	*6.6*	*4*	*3.8*
Viral sepsis infection	*1*	*0.2*	*1*	*1.0*	-	-	-	-	-	-	-	-
Total	1088		180		109		325		268		206	
Number of other medical conditions												
None	185	31.5	33	31.7	25	35.7	62	35.9	39	28.7	26	24.8
One condition	160	27.2	37	35.6	21	30.0	32	18.5	40	29.4	30	28.5
Two conditions	101	17.2	12	11.5	14	20.0	37	21.4	16	11.8	22	21.0
Three conditions	69	11.7	12	11.5	6	8.6	21	12.1	20	14.7	10	9.5
Four conditions	47	8.0	7	6.7	3	4.3	13	7.5	14	10.3	10	9.5
Five conditions	15	2.5	-	-	1	1.4	4	2.3	4	2.9	6	5.7
Six or more conditions	11	1.9	3	2.9	-	-	4	2.3	3	2.2	1	1.0
Total	588	100.0	104	100.0	70	100.0	173	100	136	100.0	105	100.0
Developmental delays												
None	82	13.9	14	13.5	14	20.0	21	12.1	13	9.6	20	19.0
Cognitive	368	62.6	78	75.0	44	62.9	103	59.5	92	67.6	51	48.6
Language	399	67.9	66	63.5	37	52.9	121	69.9	107	78.7	68	64.7
Social	302	51.4	52	50.0	23	32.9	103	59.5	83	61.0	41	39.0
Fine motor	414	70.4	70	67.3	47	67.1	126	72.8	107	78.7	64	61.0
Gross motor	438	75.0	79	76.0	46	65.7	141	81.5	98	72.1	74	71.0
Adaptive	306	52.0	59	56.7	27	38.6	92	53.2	73	53.7	55	52.4
Total	2309		418		238		707		573		373	

Table 35, continued

Child characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Number of developmental delays												
None	82	13.9	14	13.5	14	20.0	21	12.1	13	9.6	20	19.1
One domain	52	8.9	15	14.4	6	8.5	13	7.5	10	7.3	8	7.6
Two domains	62	10.5	3	2.9	7	10.0	22	12.7	12	8.8	18	17.1
Three domains	51	8.7	7	6.7	7	10.0	15	8.7	14	10.3	8	7.6
Four domains	45	7.6	7	6.7	10	14.3	8	4.6	13	9.6	7	6.7
Five domains	64	10.9	14	13.5	13	18.6	18	10.4	12	8.8	7	6.7
All six domains	232	39.5	44	42.3	13	18.6	76	44.0	62	45.6	37	35.2
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Level of vision												
Meets definition of blindness	78	13.3	8	7.7	9	12.8	27	15.6	11	8.1	23	21.9
Functions at definition of blindness	127	21.6	29	27.9	10	14.3	34	19.7	14	10.3	40	38.1
Low vision	241	41.0	47	45.2	34	48.6	60	34.7	66	48.5	34	32.4
Typical or near typical	142	24.1	20	19.2	17	24.3	52	30.0	45	33.1	8	7.6
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Level of support needs												
Typical support needs	81	13.8	10	9.6	15	21.4	22	12.7	13	9.5	21	20.0
Mild/moderate support needs	294	50.0	42	40.4	36	51.4	95	54.9	67	49.3	54	51.4
Intensive support needs	213	36.2	52	50.0	19	27.2	56	32.4	56	41.2	30	28.6
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Primary learning channel												
Visual	274	57.7	18	58.1	40	63.5	100	62.9	78	61.9	38	39.6
Tactual	57	12.0	8	25.8	7	11.1	15	9.4	19	15.1	8	8.3
Auditory	144	30.3	5	16.1	16	25.4	44	27.7	29	23.0	50	52.1
Total	475	100.0	31	100.0	63	100.0	159	100.0	126	100.0	96	100.0

Table 35, continued

Child characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Missing/unreported/unknown	113	19.2	73	70.2	7	10.0	14	8.1	10	7.4	9	8.6

Note. Some percentages do not total 100.0 due to rounding. *Italics* indicate subcategories of major categories. Percentages not always reported because more responses were indicated for the variable. Cortical Visual Impairment/Delayed Visual Maturation (CVI/DVM), Optic Nerve Hypoplasia (ONH), Retinopathy of Prematurity (ROP), Leber's Congenital Amaurosis (LCA), familial exudative vitreous retinopathy (FEVR), Ocular Motor Apraxia (OMA), persistent hyperplastic primary vitreous (PHPV), Cerebral Palsy/Orthopedic Impairment (CP/OI), Autism Spectrum Disorder (ASD), Gastroesophageal reflux disease (GERD)

Table 36

Descriptive Statistics for Family Characteristics-Categorical Variables

Family characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**N**	**%**	**N**	**%**	**N**	**%**	**n**	**%**	**n**	**%**
Ethnicity (n = 667)												
White	325	48.7	48	34.8	36	51.4	61	31.8	107	70.4	73	63.5
Hispanic	181	27.1	46	33.3	7	10.0	87	45.3	27	17.8	14	12.2
Black	49	7.3	4	2.9	21	30.0	8	4.2	5	3.3	11	9.6
Native American	45	6.7	5	3.6	-	-	28	14.6	9	5.9	3	2.6
Asian	32	4.8	17	12.3	1	1.4	7	3.6	2	1.3	5	4.3
Pacific Islander	19	2.8	13	9.4	-	-	-	-	1	0.7	5	4.3
Missing/unreported	11	1.6	4	2.9	4	5.7	-	-	1	0.7	2	1.7
Middle Eastern	5	0.7	1	0.7	1	1.4	1	0.5	-	-	2	1.7
Total	667		138		70		192		152		115	
Number of ethnic groups												
One group	512	88.7	74	71.2	66	94.3	156	90.2	120	88.3	96	91.4
Two groups	54	9.4	20	19.2	-	-	15	8.7	15	11.0	4	3.8
Three or more groups	11	1.9	6	5.8	-	-	2	1.1	-	-	3	2.9
Total	577	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Missing/unreported	11	1.9	4	3.8	4	5.7	-	-	1	0.7	2	1.9
Age of biological mom at birth (years)												
15-19	38	9.4	3	3.3	1	12.5	19	16.4	9	9.0	6	6.9
20-29	198	49.2	33	35.8	4	50.0	58	50.0	56	56.0	47	54.0
30-39	144	35.7	48	52.2	3	37.5	32	27.6	31	31.0	30	34.5
40-46	23	5.7	8	8.7	-	-	7	6.0	4	4.0	4	4.6
Total	403	100.0	92	100.0	8	100.0	116	100.0	100	100.0	87	100.0
Missing/unreported	185	31.5	12	11.5	62	88.6	57	33.0	36	26.5	18	17.1

Table 36, continued

Family characteristic	All		CA		MD		NM		UT		WA	
	n	%	n	%	n	%	n	%	n	%	n	%
Age of biological dad at birth (years)												
16-19	12	3.4	-	-	-	-	8	9.0	3	3.4	1	1.2
20-29	140	40.1	17	20.8	2	33.3	40	44.4	44	50.0	37	44.6
30-39	157	45.0	50	61.0	4	66.7	30	33.3	32	36.4	41	49.4
40-49	38	10.9	14	17.0	-	-	12	13.3	9	10.2	3	3.6
50-56	2	0.6	1	1.2	-	-	-	-	-	-	1	1.2
Total	349	100.0	82	100.0	6	100.0	90	100.0	88	100.0	83	100.0
Missing/unreported	239	40.7	22	21.1	64	91.4	83	48.1	48	35.3	22	21.0
Child's caregiver												
Two biological parents	431	73.4	86	82.7	52	74.3	114	65.9	105	77.2	74	71.1
Single biological parent	105	17.9	14	13.4	16	22.9	40	23.1	17	12.5	18	17.3
Related adults(s)	10	1.7	-	-	-	-	4	2.3	-	-	6	5.8
Foster family	24	4.1	3	2.9	1	1.4	10	5.8	5	3.7	5	4.8
Unrelated adult(s)	2	0.3	-	-	-	-	-	-	1	0.7	1	1.0
Adoptive	11	1.9	-	-	1	1.4	2	1.2	8	5.9	-	-
Biological & step parent	4	0.7	1	1	-	-	3	1.7	-	-	-	-
Total	587	100.0	104	100.0	70	100.0	173	100.0	136	100.0	104	100.0
Missing/unreported	1	0.2	-	-	-	-	-	-	-	-	1	1.0
Grouped												
Two biological parents	435	74.1										
Single parent	105	17.9										
Other adult	12	2.0										
Foster/adoptive	35	6.0										
Total	587	100.0										
Missing/unreported	1	0.2										

Table 36, continued

Family characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
Siblings												
No siblings	316	53.7	45	43.3	38	54.0	105	60.7	73	53.7	55	52.4
One sibling	137	23.3	38	36.5	16	23.0	33	19.1	21	15.4	29	27.6
Two siblings	78	13.3	14	13.5	7	10.0	23	13.3	26	19.1	8	7.6
Three or more siblings	57	9.7	7	6.7	9	13.0	12	6.9	16	11.8	13	12.4
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Primary language												
English	478	81.6	60	58.3	58	82.9	146	84.4	120	88.9	94	89.5
Not English	108	18.4	43	41.7	12	17.1	27	15.6	15	11.1	11	10.5
Total	586	100.0	103	100.0	70	100.0	173	100.0	135	100.0	105	100.0
Missing/unreported	2	0.3	1	1.0	-	-	-	-	1	1.0	-	-
Mother's level of education												
Did not graduate high school	32	7.2	16	17.0	-	-	10	7.6	1	1.0	5	5.5
High school diploma	122	27.5	20	21.1	5	23.8	43	32.8	31	29.2	23	25.6
Associate's degree/some college	151	34.1	25	26.3	5	23.8	39	29.8	48	45.3	34	37.8
Undergraduate degree	89	20.1	23	24.2	7	33.3	20	15.3	23	21.7	16	17.8
Graduate degree	49	11.1	11	11.6	4	19.1	19	14.5	3	2.8	12	13.3
Total	443	100.0	95	100.0	21	100.0	131	100.0	106	100.0	90	100.0
Missing/unreported	145	24.7	9	8.7	49	70.0	42	24.3	30	22.1	15	14.3
Father's level of education												
Did not graduate high school	37	9.5	15	17.9	-	-	13	11.8	2	2.0	7	8.4
High school diploma	114	29.3	25	29.7	5	41.7	32	29.4	33	32.7	19	22.9
Associate's degree/some college	116	29.8	14	16.7	4	33.3	38	34.9	32	31.7	28	33.7
Undergraduate degree	80	20.6	21	25.0	1	8.3	10	9.2	31	30.7	17	20.5

Table 36, continued

Family characteristic	All		CA		MD		NM		UT		WA	
	n	%	n	%	n	%	n	%	n	%	n	%
Graduate degree	42	10.8	9	10.7	2	16.7	16	14.7	3	2.9	12	14.5
Total	389	100.0	84	100.0	12	100.0	109	100.0	101	100.0	83	100.0
Missing/unreported	199	33.8	20	19.2	58	82.9	64	37.0	35	25.7	22	20.9

Note. Some percentages do not total 100.0 due to rounding. *Italics* indicate subcategories of major categories. Percentages not always reported because more responses were indicated for the variable.

Table 37

Descriptive Statistics for Service Characteristics-Categorical Variables

Service characteristic	**All**		**CA**		**MD**		**NM**		**UT**		**WA**	
	n	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**	**n**	**%**
State												
California	104	17.7										
Maryland	70	11.9										
New Mexico	173	29.4										
Utah	136	23.1										
Washington	105	17.9										
Total	588	100.0										
Days between referral and enrollment to specialized visual impairment services												
Less than 30 days	442	75.6	82	78.8	53	75.7	142	82.1	91	67.0	74	70.5
More than 30 days	143	24.4	22	21.2	17	24.3	31	17.9	45	33.0	28	26.6
Total	585	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Missing/unreported	3	0.5	-	-	-	-	-	-	-	-	3	2.9
Referral source												
EI program/Child Find	457	78.1	63	61.8	55	79.7	131	75.7	113	83.1	95	90.5
Medical	98	16.8	30	29.4	10	14.5	34	19.7	20	14.7	4	3.8
Family	30	5.1	9	8.8	4	5.8	8	4.6	3	2.2	6	5.7
Total	585	100.0	102	100.0	69	100.0	173	100.0	136	100.0	105	100.0
Missing/unreported	3	0.5	2	2.0	1	1.4	-	-	-	-	-	-
Visual impairment service provider												
Certified teacher of VI	332	56.5	15	14.5	69	98.6	33	19.1	122	82.4	103	98.1
Other professional trained by VI program	209	35.5	70	67.0	1	1.4	120	69.3	18	13.2	-	-

Table 37, continued

Service characteristic	All		CA		MD		NM		UT		WA	
	n	%	n	%	n	%	n	%	n	%	n	%
Certified O&M specialist	11	1.9	11	10.7	-	-	-	-	-	-	-	-
Deaf blind specialist	3	0.5	-	-	-	-	-	-	3	2.2	-	-
CTVI/O&M	22	3.7	-	-	-	-	18	10.4	2	1.5	2	1.9
CTVI/DB specialist	6	1.0	4	3.9	-	-	1	0.6	1	0.7	-	-
CTVI/DB/O&M	1	0.2	-	-	-	-	1	0.6	-	-	-	-
Certified vision rehabilitation therapist	4	0.7	4	3.9	-	-	-	-	-	-	-	-
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Frequency of visual impairment service												
Weekly	91	15.5	47	45.2	2	2.8	21	12.1	18	13.2	3	2.8
Bi-weekly	209	35.5	50	48.1	11	15.7	66	38.2	61	44.8	21	20.0
Monthly	243	41.3	6	5.7	30	42.9	82	47.4	53	39.0	72	68.6
Quarterly	29	5.0	-	-	17	24.3	4	2.3	-	-	8	7.6
Other	3	0.5	1	1.0	-	-	-	-	1	0.7	1	1.0
Bi-monthly	9	1.5	-	-	6	8.6	-	-	3	2.3	-	-
Annual	1	0.2	-	-	1	1.4	-	-	-	-	-	-
Consultation as needed	3	0.5	-	-	3	4.3	-	-	-	-	-	-
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Location of visual impairment service												
Home	464	78.9	64	61.5	45	64.3	136	78.6	122	89.7	97	92.3
VI program/agency	9	1.5	-	-	1	1.4	7	4.0	1	0.7	-	-
Natural environment	4	0.7	-	-	1	1.4	1	0.6	1	0.7	1	1.0
EI center	4	0.7	-	-	-	-	-	-	3	2.2	1	1.0
Residential care facility	2	0.3	-	-	-	-	-	-	1	0.7	1	1.0
Home and other	105	17.9	40	38.5	23	32.9	29	16.8	8	6.0	5	4.7

Table 37, continued

Service characteristic	All		CA		MD		NM		UT		WA	
	n	%	n	%	n	%	n	%	n	%	n	%
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0
Early intervention services (n=588 with 1415 total services provided)												
Physical therapy	361	61.4	74	71.2	57	81.4	102	59.0	90	66.2	38	36.2
Occupational therapy	354	60.2	56	53.8	45	64.3	118	68.2	73	53.7	62	59.0
Special instruction	344	58.5	75	72.1	39	55.7	134	77.5	72	52.9	24	22.9
Speech/language services	194	33.0	11	10.6	10	14.3	98	56.6	43	31.6	32	30.5
None	42	7.1	10	9.6	5	7.1	10	5.8	6	4.4	11	10.5
Deaf/hard of hearing	23	3.9	5	4.8	4	5.7	2	1.2	8	5.9	4	3.8
Other:	97	16.6	14	13.5	7	10.0	42	24.3	29	21.3	5	4.8
Social work	*30*	*5.1*	*3*	*2.9*	-	-	*19*	*11.0*	*6*	*4.4*	*2*	*2.0*
Nursing	*25*	*4.3*	*1*	*1.0*	*6*	*8.6*	*5*	*2.9*	*13*	*9.6*	-	-
Other Non-IDEA service	*25*	*4.3*	*4*	*3.8*	-	-	*12*	*6.9*	*9*	*6.6*	-	-
Feeding/nutrition	*8*	*1.4*	*3*	*2.9*	-	-	*3*	*1.7*	-	-	*2*	*2.0*
Psychological	*6*	*1.0*	*3*	*2.9*	-	-	*1*	*0.6*	*1*	*0.7*	*1*	*1.0*
Assistive technology	*2*	*0.3*	-	-	*1*	*1.4*	*1*	*0.6*	-	-	-	-
Applied behavior analysis	*1*	*0.2*	-	-	-	-	*1*	*0.6*	-	-	-	-
Total	1415		245		167		506		321		176	
Number of early intervention services												
None	42	7.1	10	9.6	5	7.1	10	5.8	6	4.4	11	10.5
One service	124	21.1	20	19.2	11	15.7	15	8.7	31	22.8	47	44.8
Two services	165	28.1	26	25.0	24	34.3	44	25.4	42	30.8	29	27.6
Three services	135	23.0	30	28.9	20	28.6	43	24.8	28	20.6	14	13.3

Table 37, continued

Service characteristic	All		CA		MD		NM		UT		WA	
	n	%	n	%	n	%	n	%	n	%	n	%
Four or more services	122	20.7	18		10		61	35.3	29	21.3	4	3.8
Total	588	100.0	104	100.0	70	100.0	173	100.0	136	100.0	105	100.0

Note. Some percentages do not total 100.0 due to rounding. *Italics* indicate subcategories of major categories. Percentages not always reported because more responses were indicated for the variable. Early Intervention (EI), Visual Impairment (VI), Orientation and Mobility (O&M), Certified Teacher of Students with Visual Impairment (CTVI), Deaf-Blind (DB), Individuals with Disabilities Education Act (IDEA)

Table 38

Measures of Central Tendency for Child, Family, and Service Characteristics-Continuous Variables

Continuous variable	All	CA	MD	NM	UT	WA
Birth weight (pounds)						
Mean	5.98	6.5	6	5.5	5.7	6.5
Variance	5					
Standard deviation	2.24	2.2	2.3	2	2.3	2.3
Minimum	1.1	1.2	1.1	1.2	1.1	1.5
Maximum	15.2	15.2	11	10.6	9.8	11
Sample size (*n*)	499	101	62	144	98	94
Missing/unreported (*n*)	89	3	8	29	38	11
Age of biological mom at birth (years)						
Mean	28.3	31	28.6	27.2	27.6	27.7
Variance	40.1					
Standard deviation	6.3	5.9	7	6.9	5.7	5.8
Minimum	15	18	19	15	16	16
Maximum	46	54	39	43	40	41
Sample size (*n*)	443	95	21	131	106	90
Missing/unreported (*n*)	145	9	49	42	30	15
Age of biological dad at birth (years)						
Mean	31.2	34.2	32.2	29.9	30	30.7
Variance	48.2					
Standard deviation	6.9	6.5	3.4	7.7	6.4	6.6
Minimum	16	21	28	16	18	16
Maximum	56	54	36	49	44	56

Table 38, continued

Continuous variable	**All**	**CA**	**MD**	**NM**	**UT**	**WA**
Sample size (*n*)	389	84	12	109	101	83
Missing/unreported (*n*)	199	20	58	64	35	22
Service characteristic						
Age of visual diagnosis (months)						
Mean	7.2	5.5	6.1	8.8	6.3	8.1
Variance	42.7					
Standard deviation	6.5	5.4	6.6	7.4	5.2	6.7
Minimum	0	0	0	0	0	0
Maximum	36	25.4	17	36	24	29.4
Sample size (*n*)	502	85	64	144	112	97
No diagnosis (*n*)	85	19	6	29	23	8
Missing/unreported (*n*)	1				1	
Months between diagnosis of visual impairment and referral to specialized visual impairment services						
Mean	5.2	6	5.9	3.2	4.8	6.2
Variance	33.6					
Standard deviation	5.8	6.3	6.6	3.6	6	5.8
Minimum	0	0	0	0	0	0.1
Maximum	26.1	24.4	25.7	28.9	26.1	22.6
Sample size (*n*)	348	73	53	71	79	72
No diagnosis (*n*)	85	19	6	29	23	8
Diagnosis after referral (*n*)	152	12	10	73	33	24
Missing/unreported (*n*)	3		1		1	1

Table 38, continued

Continuous variable	All	CA	MD	NM	UT	WA
Age of referral to specialized visual impairment services (months)						
Mean	9.5	10	10	7.4	9.3	12.4
Variance	50.3					
Standard deviation	7.1	6.9	6.8	5.9	7.3	7.9
Minimum	0.2	0.2	0.5	0.6	0.4	0.2
Maximum	33.2	33.2	28	28.9	32.2	31.9
Sample size (*n*)	586	104	69	173	136	104
Missing/unreported (*n*)	2		1	1		
Age at enrollment to specialized visual impairment services (months)						
Mean	10.4	11	10.8	8.3	10	13.5
Variance	51.1					
Standard deviation	7.2	7	6.7	6.2	7.1	8
Minimum	0.2	0.2	0.9	1.1	1.2	2.5
Maximum	33.4	33.4	16.2	30	33	33.1
Sample size (*n*)	586	104	69	173	136	104
Missing/unreported (*n*)	2		1			1

APPENDIX G

PEARSON CORRELATIONS

Pearson Correlations

Table 39

Pearson Correlations of Variables with Statistical Significance

Variable group	Age of diagnosis	Age of referral
	r	*r*
Child variables		
Gestational age		
Full Term	-	.064
37 to 33 weeks gestation at birth	-	-.056
32 to 28 weeks gestation at birth	-	-.067
27 or less weeks gestation at birth	-	-.078
Unknown gestational age	-	.143
Primary eye condition		
Cortical visual impairment	.248	-.041
Optic nerve hypoplasia	-.086	-.046
Retinopathy of prematurity	-.135	-.057
Albinism	-.097	.000
Structural	-.172	-.116
Retinal	-.019	.016
Miscellaneous eye condition	.025	.136
Unknown eye condition	.037	.048
Etiology		
Prenatal	-.233	-.120
Perinatal	-.048	-.046
Postnatal	.210	.135
Unknown etiology	.125	.049

Table 39, continued

Variable group	Age of diagnosis	Age of referral
	r	*r*
Medical condition		
No medical condition	-.041	-
Neurological	.160	-
Global syndrome	-.058	-
Endocrine disorder	-.035	-
Deaf/hard of hearing	-.076	-
Feeding issues	.086	-
Other medical condition	.008	-
Family variables		
Primary caregiver		
Two biological parents	-.150	-
Single biological parent	.136	-
Other adult (related or unrelated)	.127	-
Foster/adoptive	-.012	-
Unknown	-.049	-
Service variables		
State		
California	-.119	.034
Maryland	-.067	.028
New Mexico	.157	-.195
Utah	-.074	-.014
Washington	.068	.192

Table 39, continued

Variable group	Age of diagnosis	Age of referral
	r	*r*
Referral source		
Early intervention (EI) program	-	.177
Medical professional	-	-.209
Family	-	.027
Unknown	-	-.021
Type of EI Services		
No other EI services	-.154	-
Developmental special instruction	.080	-
Occupational therapy	.125	-
Physical therapy	.096	-
Speech & language services	.230	-
Deaf/hard of hearing services	-.082	-
Other EI service	.081	-
Number of EI services		
No services	-.154	-
One other EI service	-.101	-
Two other EI services	.045	-
Three other EI services	.023	-
Four or more other EI services	.132	-

Note: Early Intervention (EI)

APPENDIX H

MULTIPLE REGRESSION RESULTS

Multiple Regression Results

Table 40

Multiple Regression Results for Age of Diagnosis

Variable group	*df*	*F*	*R*	*Rsq*	*Beta*	*p-value*
Child variables						
Primary eye condition	7, 494	8.140	.322	.103		.000
1) CVI/DVM	1, 500	32.90	.248	.062	.248	.000
2) CVI/DVM	2, 499	21.42	.281	.079	.304	.000
Misc. eye condition					.143	.002
3) CVI/DVM	3,498	16.89	.304	.092	.336	.000
Misc. eye condition					.172	.000
Unknown eye condition					.120	.007
Etiology	3, 498	14.392	.282	.080	-	.000
1) Prenatal	1, 500	28.806	.233	.054	-.233	.000
2) Prenatal	2, 499	21.079	.279	.078	-.300	.000
Perinatal					-.167	.000
Medical condition	7, 494	3.069	.204	.042		.004
1) Neurological	1, 500	13.125	.160	.026	.160	.000
Gender	1, 500	.021	.006	.000		.885
Birthweight	1, 432	3.487	.089	.008		.063
Level of vision	3, 498	1.295	.088	.008		.275
Level of developmental Needs	2, 499	1.145	.068	.005		.319
Gestational age	4, 497	1.915	.123	.015		.107
Primary sensory channel	7, 494	3.469	.143	.020		.016

Table 40, continued

Variable group	df	F	R	Rsq	Beta	p-value
Family variables						
Primary caregiver	4, 497	5.047	.198	.039		.001
1) Two biological parents	1, 500	11.522	.150	.023	-.150	.001
2) Two biological parents	2, 499	7.904	.175	.031	-.126	.006
Other related adult					.094	.041
Age of biological dad at birth	5, 496	1.616	.127	.016		.154
Mom education level	5, 496	.893	.094	.009		.485
Dad education level	5, 496	1.010	.100	.010		.411
Language	2, 499	.007	.005	.000		.993
Ethnicity	8, 492	1.179	.137	.019		.310
Presence of siblings	3, 498	.649	.062	.004		.584
Age of biological mom at birth	4, 497	1.788	.119	.014		.130
1) Thirties	1, 500	6.045	.109	.012	-.109	.014
Service variables						
State	4, 497	5.340	.203	.041		.000
1) New Mexico	1, 500	12.610	.157	.025	.157	.000
2) New Mexico	2, 499	10.310	.199	.040	.197	.000
Washington					.129	.005
Number of EI services	4, 497	5.942	.214	.046		.000
1) No services	1, 500	12.176	.154	.024	-.154	.001
2) No service	2, 499	10.302	.199	.040	-.174	.000
One service					-.128	.004
Type of EI service	7, 494	5.859	.277	.077		.000
1) Speech therapy	1, 500	27.985	.230	.053	.230	.000
2) Speech therapy	2, 499	17.247	.254	.065	.207	.000
No service					-.110	.013

Variable group		df	F	R	Rsq	Beta	p-value
3)	*Speech therapy*	3, 498	12.959	.269	.072	.205	.000
	No service					-.116	.009
	Deaf/hard of hearing services					-.088	.042

Note: Cortical Visual Impairment/Delayed Visual Maturation (CVI/DVM), Early Intervention (EI)

Table 41

Multiple Regression Results for Age of Referral

Variable group	df	F	R	Rsq	Beta	p-value
Child variables						
Primary eye condition	7, 578	2.995	.187	.035		.004
1) Misc. eye condition	1, 584	10.935	.136	.018	.136	.001
2) Misc. eye condition *Structural*	2, 583	8.352	.167	.028	.122 -.098	.000
Gestational Age	4, 581	5.019	.183	.033		.001
1) unknown	1, 584	12.235	.143	.021	.143	.001
2) unknown *Full term*	2,583	9.545	.178	.032	.172 .110	.000
Etiology	3, 582	5.411	.165	.027		.001
1) Postnatal	1, 584	10.895	.135	.018	.135	.001
2) Postnatal *Unknown*	2, 583	8.080	.164	.027	.164 .097	.000
Gender	1, 584	.011	.004	.000		.916
Birthweight	1, 495	5.102	.101	.010		.024
Medical condition	7, 578	.933	.106	.011		.480
Level of vision	3, 582	.533	.052	.003		.660
Level of developmental needs	2, 583	1.201	.064	.004		.301
Sensory channel	3, 582	1.708	.093	.009		.164
Family variables						
Age of biological mom at birth	4, 581	1.160	.089	.008		.327
Age of biological dad at birth	5, 580	1.197	.101	.010		.309

Table 41, continued

Variable group	df	F	R	Rsq	Beta	p-value
Family variables						
Mom education level	5, 580	.730	.079	.006		.601
Dad education level	5, 580	1.650	.118	.014		.145
Language	2, 583	.503	.042	.002		.605
Presence of siblings	3, 592	1.688	.093	.009		.168
Primary caregiver	4, 581	1.917	.114	.013		.106
Ethnicity	8, 576	1.928	.161	.026		.054
Service variables						
State	4, 581	9.058	.242	.059		.000
1) New Mexico	1, 584	23.011	.195	.038	-.195	.000
2) New Mexico	2, 583	17.753	.240	.057	-.151	.000
Washington					.146	.001
Referral source	3, 582	9.044	.211	.045		.000
1) Medical	1, 584	26.724	.209	.044	-.209	.000
Number of services	4, 581	1.366	.097	.009		.244
1) No services	1, 584	5.094	.093	.009	-.093	.024
Type of services	7, 578	1.981	.153	.023		.056
1) No services	1, 584	5.094	.093	.009	-.093	.024