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Understanding Mother’s Perceptions on Assessment And Educational Programming for Their Children With Cerebral Visual Impairment

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UNDERSTANDING MOTHER’S PERCEPTIONS ON ASSESSMENT AND EDUCATIONAL PROGRAMMING FOR THEIR CHILDREN WITH CEREBRAL VISUAL IMPAIRMENT

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ABSTRACT

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Brain-based visual impairment is the leading cause of visual impairment in early childhood populations in the developed world and its contribution to childhood visual impairment is increasing (Bosch et al., 2014; Dutton & Bax, 2010; Hoyt, 2007; Kong et al., 2012; Kran et al., 2019). In order to meet the needs of this population, comprehensive assessment that includes information from families and caregivers, pediatric ophthalmologists, neurodevelopmental specialists, vision professionals, and education teams is crucial for academic and functional success (Lueck & Dutton, 2015). Family input during the special education process and the transfer of knowledge from the clinical to the educational setting that the parent provides is also vital for this population. While parent participation is a mandated feature of special education programming development, parents of children with special needs (including those with visual disability) do not always participate to the extent the law presumes.

The purpose of this qualitative multiple case study was to examine the experiences of 3 participants who are mothers of children with this visual impairment, bounded together by their shared experiences at a large children's hospital in a city in the United States and participation in their children's special education programming. The researcher explored the experiences of participants in both the clinical and educational environments and ultimately their feelings on the adequacy and effectiveness of their children’s educational programming relative to their visual disability.

The results from this study revealed valuable information on the multitude of roles that mothers play across the physical, social, and emotional spaces in the lives of their children. Since comprehensive assessment and specific programming is crucial for the success of students with CVI, the results of this study helped to construct a more comprehensive picture of the outcomes of clinical and educational assessment and opportunities for collaboration with parents and families of children with CVI. It also provided a better understanding of the challenges families face, lack of resources on CVI, and a lack of qualified personnel in the field.

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My mother, Louise, whose strength, and ability to believe in me also push me to be the person she thinks I am. I love you, Mom.

My mentors and friends at the New Mexico School for the Blind and Visually Impaired. It's not just a magical, unicorn, rainbow school--it's a place that strives to do better and be better for children with blindness and visual impairments every day. Not a day goes by I don't wish I was walking in its doors followed by the bright New Mexico morning light. My work there set the stage for the pursuit of my studies and inspired me to do better and learn more. The wonderful female leaders who challenged me daily and led me to accomplish anything I dared to try, for all of you I am truly grateful.

And lastly, my father, Frank. I wish he was here to celebrate with me. Mostly, because he promised to throw me a huge party, but also because he would be really, really, proud, and probably come up with some story about how I cured childhood blindness. He was a storyteller and I aspire to learn from him, but only use them for good.

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INTRODUCTION

Cerebral visual impairment (CVI) is the leading cause of visual impairment in children in the developing world (Gorrie et al., 2019). The need for adequate screening tools and new approaches in the field of visual impairment to understand and define the visual challenges of these children is at critical mass (Kran et al., 2019). Cerebral visual impairment is a form of neurological visual impairment. Neurological visual impairment refers to a condition that originates in various areas or networks across the brain and affects the way we process visual information. Visual processing occurs in over 40% of the brain (Dutton & Jacobson, 2001). If a person has neurological issues such as stroke, traumatic brain injury, damage, or mal development prior to birth or in early childhood, there is an increased chance that their visual processing is affected.

As a certified teacher of the visually impaired (TVI) for the last 13 years, I have had many students with many different types of visual conditions. These children all come with their own unique abilities and challenges. Visual impairment is a heterogeneous low-incidence disability; however, we have evidence-based practices, methods of instruction, and assessment techniques that can serve this population effectively and successfully (Ferrell et al., 2014).

Early in my career, I encountered several students on my caseload whose visual impairment was not caused by typical visual disorders such as retinal dystrophies, congenital cataracts, or other inherited diseases of the eye. Rather, many of the children on my caseload had a brain-based visual impairment called CVI. During my graduate studies to become a TVI, I learned about CVI in respect to children with multiple disabilities and those with developmental delays. But, once I started teaching, it was clear that some of my students with a CVI diagnosis and milder disabilities showed gaps in their ability to learn, academically and socially. They also demonstrated some challenging behavioral issues that only improved when their visual needs were considered, and adaptations and modifications were put in place to address their learning needs. It occurred to me that when these students progressed into the public school system, their behavioral, social, and academic challenges might be easily misunderstood. Because their eyes appeared “normal,” it could have been difficult for their future teachers, therapists, educational teams, and administrators to identify and understand their visual impairment as a barrier to learning, even with a documented diagnosis of CVI.

As I moved from a very small, center-based model of educating children with visual impairments to a larger public school district, it was even clearer to me that students with CVI were being underserved and their needs were not being met. I saw students in classrooms with severe visual impairments who had never worn their prescription lenses (a simple intervention to provide access). I witnessed classroom teachers completely frustrated with their inability to meet their students’ needs because no one had ever explained their visual impairment (or that they even had one), and I had many students on my caseload whose parents never received accurate reports of their child’s recommended learning mediums for reading and writing. With outdated service models, lack of understanding, and little administrative oversight, it was clear that student needs were not being met adequately.

In 2017, after giving birth to my son, I moved to serving children with visual impairments, age birth to 3, on the east side of Washington state. In this area, we had about 52 children under this age category identified with visual impairments. Today, after extensive work locating children and working with pediatric ophthalmologists and early intervention agencies, there are 136 in just two local counties. Many of these children have a confirmed or suspected diagnosis of CVI (T. Gaver, personal communication, July 22, 2020). In the birth to 3 population as well, some parents had difficulty receiving information about their child's eye condition, and even those with a diagnosis of CVI were not given information about the issues their child might have because of it. Children on my caseload who were born prematurely and diagnosed with retinopathy of prematurity (ROP) that was successfully treated are at risk for milder forms of CVI (Ortibus, De Cock, et al., 2011; van Genderen et al., 2012). However, their parents were told that their child no longer had visual problems of concern and they could follow up with an optometrist in the future if they saw a need. Clinically and socially, these children exhibited problems wayfinding and navigating their environments. They had difficulty making and sustaining eye contact and visual attention with people and moving and stationary objects and early learning materials.

Throughout my work in the special education doctoral program at the University of Northern Colorado (UNC), I have established myself as a member of the field of blindness and visual impairment willing to dedicate energy to studying populations of students with CVI. During the Summer of 2019, I was at an international workgroup on CVI hosted by the American Printing House for the Blind (APH) in Louisville, Kentucky. Representatives from a large midwestern U.S. children's hospital's Division of Pediatric Ophthalmology were also in attendance. The children's hospital was not located in Kentucky. We discussed their dedication to work with researchers and recruiting participants who would be willing to work with me on my dissertation work. Because they have a substantial pool of children diagnosed with documented CVI and very involved parents and caregivers, their clinic seemed like a good opportunity from which to recruit participants for a future study. The ophthalmologists also perform comprehensive examinations and CVI-specific assessments on their patients. As a note, the participants' children in this study are all patients at the children's hospital ophthalmology clinic; they will be referred to as "students" in the educational context and "children" regarding their relationship with the participants throughout this paper. The clinic's holistic approach to assessment and family participation during evaluation makes their process an ideal one to form the most comprehensive picture possible of these children. It is also valuable to discern how effective this process is for families and how it translates to educational programming and planning.

Without this comprehensive approach to assessment and a foundational knowledge of its implications on learning, it is virtually impossible for educational teams to meet the unique needs of students with CVI. There is no way my students could compete on an equal basis with their typically developing peers if their teachers did not understand how their visual processing differences affect their ability to access their environments and their learning and recreational materials. Because I have seen students mislabeled with behavior disorders, watched their families struggle to receive services, and witnessed their basic visual needs not being met, I am interested in understanding the extent to which information about a student's CVI is gathered from clinical and educational assessments and parent/caregiver input and how that information is translated into their special education programming and instruction. As I have conducted literature reviews and thought and extensively researched the area of CVI and strategies for successful learning, it has occurred to me that there is much work to do in the ways in which we teach educational staff, apply assessments to intervention, and consider the roles that families play in creating successful educational programming for our students. As the leading cause of visual impairment in children in the developing world (Babiescount, 2017; Dutton & Bax, 2010; Gorrie et al., 2019; Hatton et al., 2013; Kong et al., 2012), there is a dire need for adequate screening tools, new approaches, and comprehensive educational programming to understand and define the visual challenges and effective learning strategies for this population. The purpose of this study was to investigate families[1]' experiences with educational and clinical assessments and how their child's visual functioning and profile of challenges related to CVI is integrated into their educational programming and documentation.

Background of the Problem: What is Cerebral Visual Impairment?

Cerebral visual impairment is a form of neurological visual impairment. Neurological visual impairment refers to a condition that originates in various areas or networks across the brain and affects the way visual information is processed (Lueck & Dutton, 2015). When compared to other common causes of childhood visual impairment such as cataracts and ROP, which now have more effective treatments, the relative contribution of CVI to childhood visual disability is increasing (Bosch et al., 2016; Dutton & Bax, 2010; Hoyt, 2007; Kong et al., 2012; Kran et al., 2019). This increase is attributed to advancements in medical technology used to treat preterm and at-risk infants who are surviving at increased rates in both the developed and developing worlds.

The study of neurological visual processing disorders is a relatively new area. The term CVI was coined nearly 30 years ago to originally denote "visual deficits of visual perception in children" (Ortibus, De Cock, et al., 2011, p. 3). There are several different terms for this type of

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[1] The term "family" is used in this paper to represent the diversity of family members that might be responsible for a child. See definitions of terms list for more details.

visual impairment. The usage of terminology is related to region, with North American and European researchers employing different terms as well as different approaches to the identification and diagnosis (Frebel, 2006; Ortibus et al., 2019; Sakki et al., 2018). Cortical visual impairment is a popular term in the United States. In Europe, cerebral visual impairment (also, CVI) is accepted because it includes the entire region of the brain that is actively involved in how we receive, process, and make sense of visual information (Ortibus, De Cock, et al., 2011). This, though, has its own limitations because a "purely anatomical reference" (Zihl & Dutton, 2016, p. 63) does not exclusively reference the central visual system and because children with CVI also demonstrate dysfunctions that affect visual processing.

The terms neurologic and brain-based visual impairment are also used to include anyone with a neurological insult and all areas of the brain that may be affected. Most of the literature reviewed for this study used the term "cerebral visual impairment" and is written as the acronym CVI as it appears in the literature. There are, however, numerous terms for CVI including; cortical blindness, cerebral visual disturbance, visual dysfunction, visual processing disorder, higher visual functioning deficits (HVFD), brain-based visual impairment, dorsal stream dysfunction (DSD) (Bennett et al., 2020; Dutton, 2013; Dutton & Jacobson, 2001), neurological visual impairment, cognitive visual dysfunction, and retinogeniculate visual loss (Sakki et al., 2018). For the purposes of this study, the term CVI is used due to its frequency and utilization in the literature reviewed and its broader application for understanding the disorder.

Assessment

Experts and professionals in the field of blindness and visual impairment have worked for the past 30 years to understand and serve students with CVI. As stated above, CVI is the leading cause of visual impairment in childhood populations in the developed world (Babiescount, 2017;

Dutton & Bax, 2010; Gorrie et al., 2019; Hatton et al., 2013; Kong et al., 2012). It is widely understood that the only successful clinical treatment and educational interventions for CVI are based on comprehensive, ongoing assessment followed by the integration of assessment findings into instruction and environmental and material accommodations and adaptations. Cerebral visual impairment can only be managed effectively and improved upon if comprehensive assessment and programming are instituted at the earliest age possible (Dutton et al., 1996; Lehman, 2012; Ortibus, De Cock, et al., 2011). Ideally, comprehensive ophthalmological exams, neuroimaging, and medical records are reviewed as part of the comprehensive history-taking strategy when assessing children. This has been demonstrated as best practice in clinical and educational arenas (Dutton & Bax, 2010; Ortibus, De Cock, et al., 2011; van Genderen et al., 2012). The most useful information for families and children has been a comprehensive approach that includes medical and clinical history and uses both structured history-taking and formalized questionnaires. Comprehensive assessment also includes formalized functional vision assessment (FVA) and learning media assessments (LMA) which are conducted by TVIs who have a unique skill set in determining functional vision and accessible sensory information in learning and community environments.

Educational Assessment

Educational teams have two primary responsibilities: (1) to determine if a student is eligible for special education and related services, and (2) to identify current levels of a child's strengths, abilities, and needs. These responsibilities and roles must be pursued in accordance with the Individuals with Disabilities Education Act (IDEA) (IDEA, 2004) guidelines. Evaluations are conducted by trained teams of personnel and chosen according to each student’s disability-specific areas and overall cognitive function. Assessment instruments must be valid and reliable (Lewis & Allman, 2016). Few tests of aptitude are valid and reliable for students with visual impairments. It is difficult to find personnel who are qualified to adapt tests for this population. It is also difficult to find valid and reliable tools to assess the cognitive and other abilities of children with CVI (Chang & Borchert, 2020; T. Pawletko, personal communication, March 7, 2020). Teachers of students with visual impairment are frequently the coordinators of the assessment team for students with any visual disability. Their role is to help the team understand the impact of visual impairment on learning. They also provide testing accommodations and interpretations as needed (Lewis & Allman, 2016).

Unfortunately, the knowledge base of vision professionals when it comes to the assessment and instruction of students with CVI is not always adequate to meet their students' unique needs. In a recent survey of 419 TVIs across the United States, Mazel et al. (2019) found the majority of the teachers surveyed felt they had little to no training in their university programs in the proper assessment and instruction of students with CVI. Though CVI has been a visual diagnosis in children for over 30 years, there is still a demonstrated struggle for appropriate assessment and programming. In their 2010 survey of parents, Jackel et al. (2010) found that parents had to do research themselves to get the necessary supports and appropriate intervention for their children.

> These parents reported that the primary reason they had difficulty obtaining an appropriate education for their children was physicians' and teachers' lack of understanding, knowledge, and training with regard to CVI. Comments such as "the child sees well enough"; "the child does not have a true visual impairment because he [or she] has a normal eye examination"; or "CVI will resolve, and your child will no longer be

> considered visually impaired" were the three main misunderstandings that the parents reported with regard to their children's CVI. (p. 620)

In a 2019 survey follow-up, Jackel concluded parents continue to have difficulties receiving appropriate accommodations and modifications for their students. And while their child's TVI appeared to have more knowledge of CVI, there is still a large gap in the knowledge of other regular education and special education teachers. How are students with CVI supposed to be effectively educated and receive a free appropriate public education (FAPE) if these knowledge gaps exist? If families must build a knowledge base of their child's disability to advocate for appropriate services and supports, then it should be a high priority to include them in special education planning and programming for their children.

Federal special education laws require all stakeholders in a child's education (student families, school personnel, and the student themselves) to participate and contribute as integral members of the student's educational team (IDEA 20 U.S.C. § 614 [e])). Despite recommendations from experts in CVI (Lueck & Dutton, 2015; McDowell, 2020; Roman-Lantzy, 2007) and federal statutes, it is difficult to find any literature in the field that provides evidence that the comprehensive clinical and functional profile of students with CVI are effectively integrated into educational programming. It is also unclear to what extent parent and caregiver input is considered and included in individualized educational programs (IEPs) and other educational planning documentation of students with CVI.

Statement of the Research Problem

Children with all forms of CVI require specific, targeted intervention developed through comprehensive assessment and built into their educational programming and goals. The literature on specific interventions based on assessment shows improvement in visual function and, in some cases, acuity (Good et al., 2012; Hoyt, 2003; Lam et al., 2010; Lantzy & Lantzy, 2010; Lueck et al., 1999; Lueck & Dutton, 2015; Matsuba & Jan, 2006; Roman-Lantzy, 2007). Children are more able to adapt and recover from aspects of CVI (Zihl & Dutton, 2016). Prerequisites for these adaptations are visual curiosity, attention, learning, memory, and executive function. However, it has been shown that simply living in the natural environment does not elicit visual improvement (Hoyt, 2003) and, thus, the importance of developing a comprehensive profile of children with CVI is of utmost importance. In other words, specific interventions that are based on a student's precise visual needs and modifications to learning materials and environment are most effective (Roman-Lantzy, 2007). These interventions are vital for improvement and progress and most effective if they are implemented in the child's daily routines and activities (Lam et al., 2010; Lueck et al., 1999; Lueck & Dutton, 2015; Roman-Lantzy, 2007; Smith et al., 2020; Zihl & Dutton, 2016). For students with visual impairment, family involvement is crucial to providing a complete, holistic approach to assessment and interventions (Goodman & Wittenstein, 2003). Furthermore, for students with CVI, family input should be the priority as it provides the most optimal approach to learning about the abilities of the child and their comfort levels in certain environments (Zihl & Dutton, 2016). While it is acknowledged that family participation is important and leads to better outcomes for students with visual impairments and other disabilities (Goodman & Wittenstein, 2003; Lewis & Allman, 2016; Stoner et al., 2005; Turnball et al., 2006), the academic literature is scarce on integrating family input into assessment and IEP documentation and programming specifically for students with CVI.

Careful integration of assessment results and considerations are important for all students with disabilities; but for children with any type of visual impairment, they are especially vital.

These students might not be receiving the educational services they require due to coexisting learning and other disabilities, or they might be receiving services for visual impairment, but they have not been assessed for potential disability in other areas (Fellinger et al., 2009; Van den Broek et al., 2006). Evaluation for students with visual disabilities involves more than just typical academic and achievement testing. Students with visual disabilities require assessment for appropriate learning media, necessary accommodations for access to class materials and activities, and instruction in the expanded core curriculum (ECC) (Lewis & Allman, 2016). Much of the evaluation, particularly for those students with multiple impairments who have higher risk for CVI, requires careful observations in a variety of environments. Survey interviews and inventories completed by parents, students, and educators are key to developing programming and instruction that leads to educational success (Goodman & Wittenstein, 2003).

It is known that consistent interventions embedded throughout daily routines are the cornerstones of effective instruction for children with CVI (Lam et al., 2010; Smith et al., 2020; Zihl & Dutton, 2016). The most effective teaching interventions for this population combine clinical understanding of visual deficits, developmental understanding of the child’s abilities, and awareness and practical approaches to assist with missing, overwhelming, or unreliable information from the environment. There is very little literature as to whether student educational documentation such as goals and objectives, provision of supports, and appropriate accommodations are created in this manner. There is also little to no information as to how educational assessments (including FVAs, LMAs communication, social and behavioral, areas of the ECC for students with visual impairment, and assessments specific to CVI) are incorporated into student goals, adaptations, and information. These assessments joined with family input help educational teams to provide comprehensive services for students with CVI. Parental understanding of CVI has increased in the last 20 years. There is still evidence that special and general educational teams who have students with CVI in their classrooms do not receive information about CVI. Other service providers such as occupational therapists, psychologists, speech-language pathologists, or physical therapists do not get comprehensive information about CVI unless it is explicitly taught to them by a TVI or they seek out the information themselves (Ely & Ostrosky, 2017; Jackel, 2019; Jackel et al., 2010; Mazel et al., 2019). There have been no studies on parent experiences and reflections of the clinical and educational assessments and the processes of IEP programming and implementation for students with CVI.

Purpose and Rationale of the Study

The purpose of the proposed study was to examine if the educational needs of students with CVI, as perceived by their mothers and set forth by clinical and educational documentation, are represented in their academic and functional goals and programming. This research served to identify how educational services match a student's CVI profile. This profile is created from the clinical and educational assessments that the team created during the educational planning and implementation process. Research on this topic shed light on the processes involved in the creation and implementation of education programming for students with CVI. This study also explored mothers' perceptions of their experiences advocating and supporting their children with CVI and their role as members of their child's educational team. Since comprehensive assessment and specific programming is crucial for the success of students with CVI, the results of this study constructed a comprehensive picture of the outcomes of clinical and educational assessment and opportunities for collaboration with families of children with CVI. It also served to help us better understand the barriers or pathways to create successful educational outcomes for students with CVI.

Research Questions

Q1 What are the mothers' experiences of their child's special education programming and goals for meeting their CVI-specific needs?

Q2 How does the mother's understanding and knowledge of CVI contribute to the educational programming or services provided?

Q3 How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?

This study took place in collaboration with a pediatric ophthalmology clinic located in a major city in the midwestern U.S. The ophthalmologists and clinical research coordinator shared de-identified information from the pool of patients who meet the study criteria.

Definition of Terms

The following terms are defined for use in this study:

Cerebral/cortical visual impairment is defined as "impaired vision that is due to bilateral dysfunction of the optic radiations or visual cortex or both. It can coexist with ocular and ocular motor disorders and can be the result of perinatal brain dysfunction or be caused by trauma" (Roman et al., 2010, p. 69).

Family is used in this paper to represent study participants who span a diverse range of individuals with the primary responsibility for a child's health, well-being, and education. These individuals could include grandparents, aunts, uncles, foster families, siblings, or guardian ad litems among others (Mueller, 2017).

Free appropriate public education (FAPE) is the free appropriate public education provided by the public-school system. This is guaranteed to the student and their family according to the IDEA (IDEA, 20 U.S.C. § 140[a][18]).

The individualized education program (IEP) is the blueprint for educational services for students with disabilities. This plan is reviewed and revised annually by the IEP team (parent, general education teacher, special education teacher, diagnostician, administrator, and other related or instructional services as appropriate). The plan ensures a FAPE in the least restrictive environment (LRE).

Individuals with Disabilities Education Act (IDEA) is the federal law that mandates provision of special education programs for children with disabilities ages 0-21.

Least restrictive environment (LRE) guarantees that every public agency ensures that "to the maximum extent appropriate, children with disabilities are educated with children who are non-disabled" (IDEA, 20 U.S.C. §300.114[b]).

Legal blindness is a clinical definition of visual ability created by the United States in the 1930s for purposes of assessing an individual's eligibility for services. Defined as having a "central visual acuity of 20/200 or less in better eye after best correction with conventional spectacle lenses; or visual acuity better than 20/200 if there is a field defect in which the widest diameter of the visual field is no greater than 20 degrees" (American Foundation for the Blind, n.d.).

Supplementary aids and services established by IDEA (2004) are supports that are provided in regular education, education-related and non-academic settings that enable children with disability to be educated with nondisabled children in the LRE. (§§ 300.114 - 116). supplementary aids and services are listed in a section of a child's IEP.

Vision specialists refers to the professionals educated in the field of serving students with blindness and visual impairment. They include TVIs, certified orientation and mobility specialists (COMS), and vision rehabilitation therapists (VRTs)

Visual impairment including blindness (for educational services) refers to an impairment in vision, even with correction, that adversely affects a child's educational performance. The term includes both partial sight and blindness.

List of Acronyms

LEA	Lead education agency
FDB	Functions at the definition of blindness
ROP	Retinopathy of prematurity
FMRI	Functional magnetic resonance imaging
ECC	Expanded core curriculum
FVA	Functional vision assessment
LMA	Learning media assessment

Summary

In this chapter, I introduced CVI and the complexities of diagnosis and assessment. I relayed my personal and professional experiences and motivations for pursuing my area of study. The genesis of this study was a chance meeting at an international workgroup on CVI where I was introduced to personnel from a large children's hospital in a major midwestern US city.

I reviewed the purpose of the study and introduced the need for comprehensive assessment in order to understand the complex diagnosis of CVI. I also explained what CVI is and the complexities of its definition and naming conventions from the literature reviewed. I demonstrated the need for qualified personnel to serve students with CVI and the difficulties that families have obtaining resources and qualified personnel who can serve their students. I outlined the positive outcomes of early diagnosis and intervention and the progress that can be achieved with comprehensive and holistic approaches.

I’ve also included a statement of the research problem. The purpose and rationale for the study and definitions of terms. The significance of the study in terms of its inclusion of data from both clinical and educational settings was also presented.

CHAPTER II

REVIEW OF THE LITERATURE

In the previous chapter, I briefly explained CVI and its incidence in the population of children with visual impairments in the developed world. To fully understand CVI, it is important to understand the challenges to a CVI diagnosis, the etiology, and additional information on the eyes and the brain and how they work together to navigate and learn from the visual world. In this chapter, I will review relevant literature on CVI as a diagnosis and family participation and involvement in assessments and educational programming. I will begin by providing a background on CVI. Next, I will examine clinical and educational assessments for children with CVI. Finally, I will explore the research on educational interventions and the current literature on family participation in special education programs, paying particular attention to populations with sensory disability. The review of the literature will frame the topic to help the reader understand the purpose of this study: to investigate the experiences of families of children with CVI and how their child’s CVI profile and needs are addressed within their special education programming and instruction.

Cerebral Visual Impairment

Prevalence of Cerebral Visual Impairment

As previously mentioned, CVI is the leading cause of visual impairment in young children in the developed world. Recent studies have shown that CVI is evident in large populations of children with neurodevelopmental disorders, whether they have an official diagnosis or not (Gorrie et al., 2019; Rahi, 2007; Rahi et al., 2003). Worldwide visual impairment has decreased since the 1990s, but CVI continues to rise in the developed world (Martín et al., 2016). The prevalence of this disorder illuminates the importance of advancing research and determining the experiences of the individuals affected by it. Cerebral visual impairment can be caused by a number of issues, both common and rare in early childhood.

Causes of Cerebral Visual Impairment

There are several risk factors that give some indication of the presence of suspected CVI. In the infant population, perinatal hypoxic-ischemic injury is the most common cause of early neurological injury. In premature birth (infants born between 24-32 weeks gestational age), damage to the white matter of the brain, periventricular leukomalacia (PVL) (now more commonly called white matter damage of immaturity [WMDI]), is the leading cause of CVI in preterm infants (Chong & Dai, 2014; Flodmark et al., 1990). Other common causes of CVI include cerebral palsy, infantile seizures, brain malformations, hydrocephalus, meningitis, encephalitis, and traumatic brain injury (Dutton et al., 1996; Dutton & Jacobson, 2001; Good et al., 1994). Other contributing factors are intrauterine infection, brain development disorders, cerebral hemorrhage, and infections of the central nervous system (Boot et al., 2010; Dutton, 2013; Dutton & Jacobson, 2001; Houliston et al., 1999). Rare cases of CVI with no known origin and genetic disorders have also been identified as associated causes (Braddick & Atkinson, 2011; Itzhak et al., 2020).

In older children and adults, the diagnosis is an interdisciplinary task. Information must be gathered from a wide range of sources. These include but are not limited to: (a) comprehensive medical history, (b) ophthalmological information, (c) early interventionists and special educators, (d) observations from family, (e) responses to the environment, (f) interactions with objects and the environment, and (g) structured history-taking inventories and assessments. Additionally, an understanding of functional vision and movement abilities is necessary to develop rehabilitative, habilitative, and educational interventions (Bennett et al., 2019; Dutton et al., 1996; Gorrie et al., 2019; Lehman, 2012; Lueck & Dutton, 2015; Ortibus, De Cock, et al., 2011).

Population

Children with CVI can have additional physical abnormalities of the eye co-occurring with neurological features. If there are neurological conditions present such as stroke, traumatic brain injury, damage, or maldevelopment prior to birth or in early childhood, there is an increased chance visual processing is affected. In the literature, it is argued that disorders of visual processing should be used as diagnostic criteria for this disorder and that diagnosis alone does not describe visual abilities (Dutton, 2013; Ferziger et al., 2011; Kran et al., 2019; Ortibus, Laenen, et al., 2011; Zihl & Dutton, 2016). Because of conflicting terminology and a lack of objective diagnosis and assessment techniques, there is a consensus that more appropriate definitions of CVI be developed. After conducting a systematic literature review, Sakki et al. (2018) developed a more widely accepted definition of CVI in children as “a verifiable visual dysfunction which cannot be attributed to disorders of the anterior visual pathways or any potentially co-occurring ocular impairment” (p. 430). It is of note that currently, there is no internationally accepted definition or classification for the disorder (Sakki et al., 2018). Adequate screening tools and new approaches in the field of visual impairment are needed to understand and define the visual challenges of these children and are at critical mass (Kran et al., 2019). Treatment and progress must begin with appropriate identification and diagnosis.

Identification and Diagnosis

Currently, there is no one single test used to diagnose CVI. Most research concludes that the diagnosis of CVI should be based on functional vision processing, as opposed to landmarks and anomalies of brain structure (Bennett et al., 2019, 2020; Boot et al., 2010; Kran et al., 2019). As described above, abnormal pre- or perinatal medical history is the most important risk factor for CVI (Bennett et al., 2019; Dutton & Jacobson, 2001; Good et al., 1994). In infants, there are early signs of CVI that can be diagnosed during the first few months of life. These signs include reduced visual acuity, reduced visual fields, and malfunctioning of basic visual functions (Good et al., 2001). The diagnosis of CVI is an interdisciplinary task that should include medical, therapeutic, and educational professionals as well as family members and caregivers. To complete an entire picture of the child, their abilities, and challenges, it is recommended the team include ophthalmologists, optometrists, neuro-ophthalmologists, pediatric neurologists, early intervention and/or special education teams, and family members. Other important information that could help with identification or diagnosis include family observations, environmental responses, information on routines, and interactions with objects and visual exploration. For nonverbal or preverbal children, it is recommended that assessments include information on behavior as well (Lueck & Dutton, 2015). Assessment that considers behavioral information such as social engagement, emotional challenges, frustration, and difficulty with specific tasks and materials will elicit information on potential visual challenges. This information provides insight into processing deficits. Information is stored, retrieved, and transformed using cognitive networks (Munakata & McClelland, 2003). The outputs of these networks result in behavioral responses. If visual processing is not recognized as impacting a child’s responses to the environment, the child can be labeled with inappropriate behaviors. These conclusions could result in an inaccurate diagnosis or misdiagnosis and/or the child not receiving the appropriate interventions (Pawletko et al., 2015; Zihl & Dutton, 2016).

Associated Visual Impairments

Individuals with CVI can also exhibit ocular disorders. One of the hallmarks of CVI is no disorders of ocular origin; i.e., no obvious issues with the structure of the anterior portions of the eye. However, a few studies have shown the presence of disorders of ocular origin that accompany cognitive impairment (Hayhoe & Ballard, 2005; McClelland et al., 2006; McKillop & Dutton, 2008; Ortibus, De Cock et al., 2011). In children with CVI, bilateral reduced visual acuity is the most frequently reported visual dysfunction. The incidence of reduced acuity occurred in 30-100% of cases (Dutton et al., 1996; Fazzi et al., 2007; Roland et al., 1986). Individuals' ranges of acuity fall between normal acuity and severe, meaning very little detailed discrimination between black and white (Dutton et al., 1996; Roland et al., 1986). In addition to reduced acuity, children with CVI also demonstrate myopia, hyperopia, astigmatism, reduced contrast sensitivity, refractive errors, and errors of accommodation. Accommodation (when the lens of the eye changes shape focus from distance to near) has been verified in 50% of those with cerebral palsy (McClelland et al., 2006). This affects both near and distance acuity. Cerebral visual impairment can include peripheral field defects dependent on damage to the brain and their location (Martín et al., 2016). For example, structural brain lesions are correlated with specific visual acuity, contrast sensitivity, color detection, and field deficits (Dutton et al., 2004). It is vital that a comprehensive ophthalmological evaluation be conducted to determine corrective treatment such as prescription lenses, which will enable access to the best of the child’s abilities.

Challenges with Diagnosis

Although CVI is the most prominent cause of pediatric congenital visual impairment in the developed world, it is still profoundly undiagnosed (Lueck et al., 2019). There are numerous reasons for this. First, researchers have not developed a clear or broadly accepted understanding of the underlying neurophysiology of the condition or how brain development in CVI differs from that of ocular blindness (Bennett et al., 2019). Additionally, current categorizations of visual impairment for services are based upon visual acuity and visual field deficit measurements and do not always correspond with the visual dysfunctions of CVI (Kran et al., 2019). It is accepted knowledge in the study of CVI, across clinicians, researchers, and educators, that current definitions of blindness and visual impairment do not serve to classify individuals with CVI. The International Classification of Diseases (ICD), used for diagnosis, treatment, benefits, and billing determinations, includes only “cortical blindness” which is considered an out-of-date definition that does not reflect the wide spectrum of visual and processing impairments present in the current population of individuals with CVI (Hoyt, 2003; Kran et al., 2019; Lehman, 2012; Lueck & Dutton, 2015; Sakki et al., 2018). There is consensus, across disciplines, that the definition “should be based on functional vision rather than neuroanatomical landmarks” (Sakki et al., 2018, p. 424).

Even to the discerning eye, these types of visual impairments cannot be “seen” in non-clinical settings. A child with the issues associated with CVI may or may not tolerate glasses as an intervention. Furthermore, without a recognizable ocular impairment that resembles the typically accepted social images of what is recognized as blindness and visual impairment, many children with symptoms of CVI go undiagnosed. This is especially true in those associated with deficits in higher visual functioning. These symptoms include challenges with visual guidance of movement and complexity in visual scenes. These children would not be considered to have a “visual impairment” unless someone with knowledge about suspected medical history and behavioral manifestations is present on their educational or medical team. Furthermore, the resulting behavior from disturbances of visual perception and integration is more typical in children without a loss of visual acuity (Good et al., 1994; Zihl & Dutton, 2016). Issues with the processing of global motion perception can manifest themselves in children without brain damage, but who were born prematurely (Ortibus, De Cock, et al., 2011). These children are often left to “fall through the cracks” and could potentially miss out on diagnosis and treatment (Morse, 2018).

Identification of CVI in young children and children with multiple disabilities is also challenging due to communication issues and confounding motor and cognitive issues. Also, the population of children with CVI is heterogenous, with individuals exhibiting different challenges and abilities. Damage to the developing brain can vary based on the brain area affected and concurrent developmental trajectories.

The Spectrum of Cerebral Visual Impairment

As with many disorders, there is a spectrum of abilities and challenges in children with CVI. As stated above, diagnosis can be challenging in all groups of children with CVI because of co-existing disorders, communication challenges, and a lack of a noticeable, ocular-based issues. According to Lueck and Dutton (2015), children with CVI can be divided into the following three categories:

> Children with profound visual impairment due to CVI, many of whom have additional disabilities. Children with CVI who have functionally useful vision and cognitive

> challenges. Children with CVI who have functionally useful vision and who work at or near the expected academic level for their age group. (p. 14)

These groups can be considered “severe,” “mild,” and “moderate,” CVI. But it is important to note that there are also children that do not easily fit into these categories (Lueck & Dutton, 2015; Morse, 2018).

Children with Severe Cerebral Visual Impairment

Children with the most severe forms of CVI tend to have more profound visual impairment and a greater number of concomitant conditions. These children are often considered to have multiple impairments or multiple disabilities. Cognitively, these children tend to be severely delayed and require a wide range of clinical, therapeutic, and educational services. Children with disorders in this category with associated CVI include Fragile X Syndrome, rare genetic disorders, seizure disorders, and severe cerebral palsy (Dutton, 2013; Ferziger et al., 2011; Ortibus, De Cock, et al., 2011). Other classifications used in relation to this group are global developmental delay (GDD), profound and multiple learning difficulties (PMLD), and multiple disabilities and visual impairment (MDVI).

Children with Moderate Cerebral Visual Impairment

Children in this category can have milder CVI symptoms and co-existing motor challenges. The ability of the children in this category to show improvements in visual functioning and processing has been documented (Lam et al., 2010). These children tend to have challenges with splitting and maintaining attention, visual guidance of movement, and functioning in a busy or visually complex environment (CVI Scotland, n.d.).

Children with Mild Cerebral Visual Impairment

The word “mild” can be misleading for this population of students because without other noted disabilities, their challenges can be missed or misinterpreted, and the characteristics of their CVI are not ones that are commonly addressed through current, available methods (CVI Scotland, n.d.; Morse, 2018). Additionally, these children can exhibit clusters of behavioral responses that have the potential to be mislabeled as other behavioral disorders (T. Pawletko, personal communication, March 7, 2020). This category of CVI can go undetected until children reach school age (Lueck & Dutton, 2015). Children in this group can demonstrate relatively normal visual acuity, but still have significant challenges with higher order visual skills and, thus, fall under the umbrella of CVI and should, therefore, be included in the prevalence of the condition (Sakki, 2018).

The Visual System

Visual perception is important to the developing brain in a myriad of simple and complex ways. From recognizing a caregiver’s face to learning how to read, visual perception is the foundation on which much of our knowledge is built. Visual processing occurs in over 40% of the brain (Dutton & Jacobson, 2001). Visual processing is complex and still under scientific exploration. For individuals with typically developing visual systems, there is no indication of the complex processes the visual system undertakes when we see something. First, sensory signals (images we take in) are relayed from the retina to the visual cortex (striate cortex or area V1). These messages move from the striate onward, and the information is processed in areas called the extrastriate. The extrastriate is organized into two streams: the ventral and dorsal stream.

The Ventral Stream

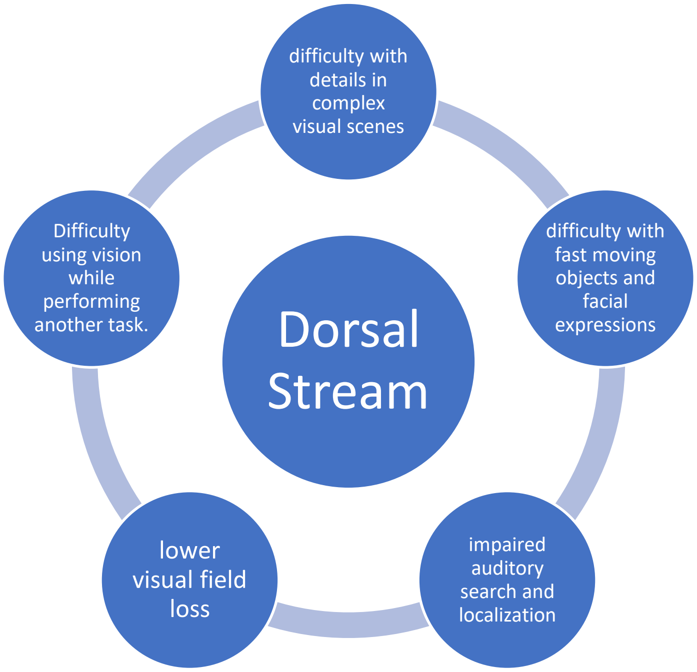
The ventral stream runs from the striate cortex to the middle and inferotemporal areas of the brain. Also called the “what” stream (Goodale & Milner, 2013), it plays a role in processing visual information such as recognizing color, objects, shapes, faces, and route finding. These representations are stored for future reference and help to build our visual memories. At this point, it is helpful to think of this system as a set of filing cabinets. The ventral stream allows for the processing of visual information which is then stored for future use so it can be accessed again and again when the information is experienced through vision and the brain can make sense of what it is and what it represents.

The Dorsal Stream

The dorsal stream, also called the “how” stream (Goodale & Milner, 2013), begins in the same area but orients its fibers to the posterior parietal cortex and processes complex visual information. It is also responsible for unconscious visible processing and allows for visual guidance of movement. Think of this as the way humans move in environments with features they have encountered before. Generally, individuals do not pay very close attention when they go up and down stairs or step off a curb. They do not have to, thanks to these marvelous processes happening all the time in the human brain. In the literature, for many years, the ventral stream and dorsal stream were divided. More recently, researchers are learning that the dorsal needs input from the ventral stream and, essentially, they develop and work together to process accurate and efficient identification and ongoing spatial location of objects and people in the environment and our interaction with them (Bennett et al., 2020; Hay et al., 2020; Maurer & Lewis, 2005). Understanding these areas of the brain and their function help us to discern the behavioral manifestations that occur as the result of their damage or maldevelopment. Children with CVI often exhibit problems with any number of the skills associated with these areas of the brain. As an infant processes information with increasing integration from these areas, they build on their ability to perceive and encode objects. This allows them to conceptualize location (dorsal) and surface features (ventral) of their world which leads to error-driven and self-organized learning. Without these basic integrations, development can look different and pose challenges for the young learner in the areas of safe and independent movement, attention, language, and learning from materials and other visual information.

Figure 1

Patterns of Behavior Associated with Visual Perceptual Disorders: Dorsal Stream



Note. *A*dapted from A. H. Lueck, and G. Dutton, (2015). *Vision and the brain: Understanding cerebral visual impairment in children*. Arlington, VA: AFB Press, American Foundation for the Blind. pp. 234-235).

Figure 2

Patterns of Behavior Associated with Visual Perceptual Disorders: Ventral Stream

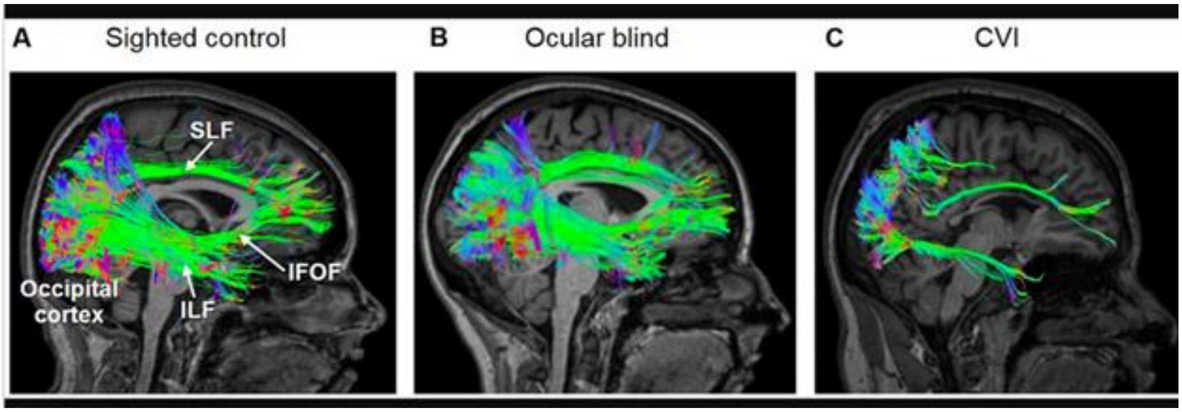
Note. Adapted from A. H. Lueck, and G. Dutton, (2015). *Vision and the brain: Understanding cerebral visual impairment in children*. Arlington, VA: AFB Press, American Foundation for the Blind. pp. 234-235).

The Cerebrally Visually Impaired Brain

It is a very exciting time to be studying CVI. Breakthroughs in the way we understand processing across neurodivergent landscapes is appearing in the literature and is recognized as a growing and much needed area of study. Much of this is due to advanced neuroimaging techniques that illuminate the ways that the brains of different individuals process visual information. Researchers at the Harvard Center for Visual Neuroplasticity conducted assessments of visual search patterns in virtual reality environments. Participants included individuals with blindness, without blindness, and those with CVI. Individuals with CVI showed marked distinctions in the way their brains process visual information. Visually complex scenes, visual integration, attention, busy visual environments, and a lack of visual search stability all affected the performance of participants with CVI (Bennett et al., 2018, 2019; Merabet et al., 2017). These researchers showed visual response and brain imaging, revealing fMRI activation patterns are less robust in individuals with CVI compared with sighted controls and individuals with ocular impairment. As demonstrated by the imaging below, neural networks connecting areas of the brain are not activated as robustly during visual processing activities in individuals with this type of impairment.

Figure 3

Imaging from The Harvard Center for Neuroplasticity



Note. Adapted from M. B. Martín, A. Santos-Lozano, J. Martín-Hernández, A. López-Miguel, M. Maldonado, C. Baladrón, C. Bauer, & L. B. Merabet, L. B., 2016, “Cerebral versus ocular visual impairment: The impact on developmental neuroplasticity,” *Frontiers in Psychology*, *7*, 1958 (https://www.frontiersin.org/articles/10.3389/fpsyg.2016.01958/full).

In total blindness, the brain adapts to a lack of vision by doing some dramatic reorganizational work. Hirsch et al. (2015) showed that, remarkably, the blind brain looks and responds very similarly to the brain with normal vision. Some areas adapt to do different things, but it responds the same way to incoming sensory information. This is not the case in the brain with CVI (Bennett et al., 2018; Merabet et al., 2017). Individuals with CVI showed greater challenges with visual search tasks, and their performance fluctuated depending on task difficulty where complexity, difficulty with efficient search patterns, and reaction times were factors. A review of the way the visual system works illuminates that if this system does not have access to reliable visual information during early development and these areas do not work together correctly, there can be differences in the way these individuals understand visual information, navigate through, and interact with it. Researchers and clinicians familiar with these challenges are still figuring out what to call this, how to diagnose it consistently, and how to explain it to the medical community at large (Lehman, 2012). There is something profoundly different in processing of information in the brain of individuals with CVI. The results from Merabet and his teams (Bennett et al., 2020; Hirsch et al., 2015), combined with the behavioral and visual challenges in this population, show that the neurological framework is affected by a disorder of processing environmental information in a typical and efficient manner. Studies using advanced brain imaging techniques suggest the contrast in ocular blindness versus CVI. According to Bennett et al., “CVI may be associated with a more generalized vulnerability implicating numerous key pathways supporting the developing visual system” (2019, p. 176).

The Effects of Cerebral Visual Impairment on Development

Development in children with CVI is widely variable and must be understood in functional contexts. School-aged children require visual processing skills to play, learn, access the environment, and other cognitive processes. While the effects of profound visual impairment and blindness on early childhood development have been studied (though not extensively), the opportunities to understand the effects of CVI on developing populations have been more limited. There is some consensus that the pattern of development in children with CVI is similar to that of blind children with co-occurring disabilities. Hatton et al. (1997) found children with blindness or very limited vision demonstrated different developmental trajectories and slower rates of skill acquisition throughout various developmental domains.

Children without vision (or with very little vision) must use and organize alternate perceptual information in the environment. Research has shown they achieve object permanence through alternate developmental routes (Fraiberg, 1977). Object permanence is crucial for the development of mental imagery. For a blind child to make use of auditory information from an object, they must develop an internal representation of the object (Fraiberg et al., 1966). Blind children make use of their senses of touch and hearing, which they can then process and apply to other situations and uses. In fact, this capacity to reach for an object using sound alone serves as an organizer of motor experience and indicates a child’s readiness to achieve increasingly independent movement (Fazzi et al., 2011)

For children to make use of the information in their environments, they must be able to efficiently access it, understand and interpret meaning, and generalize the gathered information to build representations for future use. For children with visual impairments and additional disabilities, this capacity to explore their world can be profoundly limited. During a 2011 study of blind children with and without additional disabilities and their capacity for reaching on sound cues, Fazzi et al. (2011) found that children with associated neuromotor and/or cognitive disability demonstrated limited ability to explore the environment. These children were initially checked at 3 months, up to 36 months of age. The team found that participants used their hands primarily for self-stimulation, as opposed to reaching. They rarely achieved, or achieved with significant delay, the ability to reach for objects that made sounds, though they did show excited movements in relation to sound and demonstrated difficulty to separate themselves from anchor points in the environment (moving away from a piece of furniture or getting up from the floor) (Fazzi et al., 2011). A large portion of one group in the study (94%) had a diagnosis of CVI.

In an earlier study, Pogrund and Fazzi (2002) explored early neuromotor development and found that children with visual impairment and multiple disabilities (such as cerebral palsy and intellectual disability) compared to children without additional disabilities (who all managed to achieve milestones, with delays, through the use of sound to motivate and explore movement) did not walk independently by the age of 3 years. They also did not reach toward a sound in the majority of instances presented and had marked delays in postural-motor abilities, had difficulties letting go of reference points, and displayed a “freezing” behavior in response to interesting stimuli.

It becomes easier to understand the impact of CVI on development when we can fully appreciate the ongoing sensemaking children must be able to accomplish to effectively learn and explore. Children with CVI show difficulties with several other areas of development including social skills, language, and a wide array of difficulties with academic concepts. These are explored in greater detail below.

Assessing Cerebral Visual Impairment: Challenges to Diagnosis

While extensive research using advanced neuroimaging techniques has provided remarkable information about the etiology of CVI, these tools are not always accessible to ophthalmologists, general neurologists, or other vision professionals. Another issue is that though children might demonstrate the functional characteristics of CVI, there are cases when the responsible brain injury cannot be correlated through conventional neuroimaging techniques (Lueck et al., 2019). Even if conventional neuroimaging can be used to identify the problems that could indicate a child has CVI, it does not always enable us to see the range of visual functions a child possesses. Because CVI can present differently than ocular visual impairment and doesn't always match the clinical criteria--think of ocular visual impairment as presenting with clinical evidence and CVI presenting with behavioral manifestations--it is not always identifiable and can be mislabeled as other behavioral disorders (Kran et al., 2019; Merabet et al., 2017; Pawletko et al., 2015). With such an enormous range of potential deficits, each child requires an individualized assessment of visual function to formulate an appropriate educational plan. Unfortunately, assessing visual function can be difficult in young or neurologically impaired children. Behavioral and social issues such as maintaining sustained eye contact, exhibiting challenging behavior in busy environments, and decreased visual attention do not fit into the dorsal/ventral dichotomies for identification from clinical assessment and must be gathered from history-taking and conversation with families and practitioners (Ortibus, Laenen, et al., 2011). Identification is further confounded because of a lack of objective testing modalities (Lehman, 2012). Typically, the identification of CVI comes from education professionals, parents, and clinicians who are aware of it from previous experience or knowledge of research in the area and who have a unique understanding of the child's visual functioning challenges. Many argue that this visual functioning is really what should be used as diagnostic criteria for this disorder because diagnosis alone does not describe visual abilities. (Ferziger et al., 2011; Kran et al., 2019; Ortibus, De Cock, et al., 2011; Ortibus, Laenen, et al., 2011; Ravenscroft, 2017)

Clinical Screening Practices and Procedures

There is no current consensus at an international level on how to approach the assessment of CVI in young children (Boot et al., 2010; Deramore, et al., 2016). There is wide variability in the approaches used by medical staff. Through review of the literature, it is difficult to pinpoint specific protocols and, indeed, there is new research emerging in this area (Kran et al., 2019; Lueck et al., 2019; Merabet et al., 2017; Sakki, 2018). Current literature identifies that clinical approaches to assess visual function in individuals with CVI require "significant adaptation to collect reliable data" (Merabet et al., 2017, p. 86). A pediatric ophthalmologist or optometrist needs to assess both functional vision and visual function. It is recommended that the eye care practitioner review reports from other members of the child's care team including neurodevelopmental pediatrics; neuropsychologists; neurologists; radiologists; physical, speech, language, and occupational therapies; and with ongoing communication with educators and families (Merabet et al., 2017; Sakki, 2018). At the very least, children with suspected CVI need a basic ophthalmological assessment to discern the root causes of their visual impairment, to rule out ocular disease, and to uncover any associated visual issues.

Structured Clinical History-Taking and Cerebral Visual Impairment

Structured clinical history-taking and observation for visual processing and perceptual behaviors have been shown to provide an effective and reliable method of ascertaining the nature and degree of the child's visual fields and cognitive and perceptual impairments (Philip et al., 2016). Previous work using CVI assessment tools, done primarily in Europe and India, showed reliability established by consensus amongst clinicians who are experts in the area of neurological processing disorders (Ferziger et al., 2011; Macintyre-Beon et al., 2012; Philip et al., 2016).

Dutton et al. (1996) developed a 51-item questionnaire using a structured history-taking approach using behavior related questions. It is used to screen for CVI based on clinical history and observations from parents and caregivers. Sometimes called the Structured Clinical Question Inventory (SCQUI) or CVI Questionnaire, this questionnaire provides questions that focus on visual attention behaviors, environmental challenges, field deficits (lack of vision in the peripheral fields), and the ventral and dorsal stream functions. Previous work done to validate this questionnaire or parts of it appear in the literature. Comprehensive ophthalmological exams, neuroimaging, and medical records are reviewed as part of the comprehensive history-taking strategy when assessing children. This has been shown to be best practice in clinical and educational arenas (Dutton, 2013; Ortibus, Laenen, et al., 2011; van Genderen et al., 2012). It seems the most useful information for families and children has been the comprehensive approach that uses both structured history-taking and these types of formalized questionnaires. The questionnaire has also been used by Macintyre-Beon et al. (2012) to characterize the visual behavior of children born prematurely.

Most recently, Gorrie et al. (2019) conducted an online survey of 535 parents using five questions from the SCQUI questionnaire and a 46-item CVI Questionnaire developed by Ortibus, Laenen, et al. (2011) who used it as a screening tool and correlated the questions with other diagnostic tools. This questionnaire also uses similarly organized items that sought parent observations of children’s visual behavior. The questions are similarly designed to focus on various visual and visual/cognitive processing abilities. The Ortibus, Laenen, et al. (2011) team found the questionnaire was a viable tool. The Gorrie et al. (2019) study concluded that the five questions and the questionnaire together showed good convergent reliability and internal consistency. They also found them to have a reliable factor structure. This study used factor analysis to determine construct validity and Cronbach’s Alpha to find high internal consistency. Overall and as the most crucial matter at hand, the Gorrie group’s results showed that “CVI is evident in a large proportion of children with neurodevelopmental disorders” (Gorrie, et al., 2019, p. 14). This was in populations of children who have already been diagnosed and children who have not been diagnosed but demonstrate challenges with visual processing.

In the literature, there have been numerous attempts to standardize structured, clinical history-taking strategies and use a questionnaire to record visual behaviors and characteristics. Houliston et al. (1999) used a 22-item questionnaire on 46 children with presence of hydrocephalus and 200 normally developing control participants. They found that recognition, orientation, depth analysis, simultaneous perception, detection of movement, and recognizing and describing colors were problems for children in the patient group with occipital cerebral damage. Over half of the child participants (52%) in the study exhibited evidence of cognitive visual dysfunction; they found that orientation to the environment, simultaneous perception, and motion perception were more of an issue when a child was moving through space.

Studies reviewed have looked at children with hydrocephalus, cerebral palsy (mild, moderate, and severe), and prematurity and its confounding factors. Most studies included larger numbers of normal controls versus smaller numbers of children previously diagnosed with CVI or suspected of having it. All studies reviewed reached similar conclusions: most children have more than one area of cognitive visual dysfunction. We must seek the prevalence of disorders through comprehensive, structured, history-taking procedures. The earlier the detection, the greater the opportunity for functional progress.

Currently, there is a need to expand the use of these kinds of questionnaires to support children with visual processing disorders and educate the medical, educational, and family communities served. To do so, results from previous studies require additional data analysis to understand the effects of these disorders across and within groups of children with varied medical histories, diagnoses, and visual abilities. The current study includes the largest known sample of “confirmed” cases of CVI. This study examined two groups of children assigned to a group without a CVI diagnosis and compared their scores, to the fullest extent possible, with the scores of children with a confirmed diagnosis. The importance of this lies in the challenge to use the 51-item questionnaire and understand the benefit of using it as a screening tool for all children with suspected incidence of higher visual functioning deficits.

Defining Visual Impairment

According to IDEA (2004), “visual impairment including blindness means an impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness” (§300.8). For children with CVI, impairment in vision does adversely affect their educational performance. However, even with this legal standing, outdated definitions of visual impairment, an adherence to using visual acuity measures and visual field measurements as criteria for services, children with CVI often fail to meet the inclusion criteria to receive educational services and benefits (Kran et al., 2019). The legal definition of blindness in the United States, which determines eligibility for vocational training, rehabilitation, schooling, disability benefits, low-vision devices, and tax exemption programs is “a visual acuity of 20/200 or less in the better-seeing eye with best conventional correction.” (AFB, n.d.). Cerebral visually impaired is recognized by policy makers in the field of visual impairment and blindness as eligible criteria for federal quota funds that provide funding and support to students that “functions at the definition of blindness” (FDB). Functions at the definition of blindness is defined as “visual performance reduced by brain injury or dysfunction meets the definition of blindness as determined by an eye care specialist or neurologist” (AFB, n.d.).

Even with this safeguard in place, children can be left out of supports and appropriate educational services if eligibility criteria are not met as a child with documented visual disability. Empirical and exploratory evidence shows that children with CVI need a unique set of strategies and interventions. Indeed, parent reports (Jackel, 2019; Jackel et al., 2010) convey that parents have difficulty obtaining accommodations and modifications for their children and that their children are denied services because they did not fall under the legal visual acuity for services for children with visual impairments. Additionally, data on the prevalence of the disorder must be accurately collected to provide funding and drive policy at state and federal levels.

Defining Eligibility: Special Education Services

Recall the wide spectrum of processing difficulties for children with CVI. The challenge for practitioners is how to classify and approach intervention for children with CVI so they are not at a disadvantage. In the case of children born prematurely with no brain damage, there are instances of issues with the processing of global motion processing (Ortibus, De Cock, et al., 2011). This skill can be impacted, and this population of children serves as the perfect example of the necessity to observe the behavioral functioning of children in a wide variety of environments and during everyday tasks and routines. Unfortunately, as stated above, subjective measures of assessment do not guarantee services or diagnosis from medical professionals. That is why the team approach to identification, assessment, and treatment of CVI is so vital. The sooner a child’s visual processing needs are identified, the better the opportunities for promoting functional improvement (Kran et al., 2019; Lehman, 2012; Lueck & Dutton, 2015; Zihl & Dutton, 2016).

Clinicians and special educators must show that a child’s visual dysfunction resulting from CVI “adversely affects a child’s educational performance” (IDEA §300.8). These parties may need to work together to ensure a child meets the criteria and receives the supports and accommodations they need. Including clinical vision evaluations can even be considered among the related services under IDEA because their intent is to assist a child's visual functioning within special education (Corn & Lusk, 2018). Even with a confirmed diagnosis and clinical information, there is evidence that students do not always get what they need in terms of educational support. Jackel et al. (2010) found that parents of children with CVI had to do research to gain the necessary supports and interventions to get appropriate interventions for their children. They reported the primary barrier to services was the physicians' and teachers' lack of understanding, knowledge, and training with regard to CVI. An educated team for a child with CVI must understand the tools and requirements of comprehensive assessment in order to provide adequate information which aids in developing effective educational programming.

Educational Assessment Specific to Students with Visual Impairments

Prior to instruction and intervention, the child's visual difficulties, material adaptations, and environmental accommodations must be established to meet her complex visual needs. It is the responsibility of TVIs to conduct a FVA, to establish the child's functional vision and understand its implications for learning. The TVI also conducts a LMA to determine the learning media necessary for communication and literacy purposes that will be appropriate for the student. The TVI is frequently the coordinator of the assessment team and helps all parties to understand the impact of visual impairment on learning and development. It is also their responsibility to provide accommodations for learning materials and environments and interpret information about the child's visual diagnosis. The child's education team must work together to provide daily instruction that is appropriate and accessible to the learner. The special education team has two primary responsibilities in the role of comprehensive assessment. They must determine eligibility for special education and related services and identify the student’s current level of performances--their strengths and abilities. Trained personnel must conduct these assessments based on the child’s clinical presentation and their needs.

National organizations such as the Division on Visual Impairments and Deafblindness (DVIDB) at the Council for Exceptional Children (CEC) on the education of students with disabilities have emphasized the need for FVAs and LMAs (Spungin et al., 2007), orientation and mobility (O&M) evaluations, and instruction in the use of low-vision devices be given to students and are established as the responsibilities of the vision specialist (Cmar et al., 2015). Educational decisions are not based on the results of a single test, but rather all the information gathered through the various appropriate assessments, family, and team input (Lewis & Allman, 2016).

Functional Vision Assessment

The FVA (also called Functional Visual Assessment or Functional Vision Evaluation) is the cornerstone of the student with visual impairment’s educational plan. The FVA is the cumulative report that includes the student’s existing medical/ophthalmological information and diagnosis, levels of visual functioning, and observations of the student within the school community. This information culminates into an end report that aids the team in providing support to the student through the adaptation and modification of learning materials and spaces. It helps us to understand the student’s vision and how it affects the situational experiences within their learning environments (Goodman & Wittenstein, 2003).

Learning Media Assessment

The LMA is a systematic guide to observe a student’s use of sensory information in their learning environments. It guides selection of instructional methods and the literary medium the child can use most proficiently, whether it is visual information, tactile information, auditory information, or any combination of these. The assessor must provide evidence of which sensory modes the child uses throughout daily routines and experiences and provide recommendations and planning based on these observations and their expertise.

Choosing the appropriate learning media for students with visual impairments is a vital part of the development of educational programming. The reauthorization of the IDEA Amendments of 1997 Public Law 105-17 clarified the responsibilities of public agencies in the education of students with visual impairments and blindness with respect to literacy instruction. The reauthorized statute provides that IEP teams are required to provide instruction in Braille unless the team makes the determination that it is not appropriate. The only way to make this determination is through the conduction of an LMA. This determination is only made "after an evaluation of the child's reading and writing skills" (20 U.S.C. 1414(d)(3)(B)(iii); 34 CFR 300.346(a)(2)(iii). This determination is made annually at the child's IEP meeting. Educators must understand the scope of assessments necessary for children with disabilities. The law also requires that the child be "assessed in all areas related to the suspected disability, including, if appropriate, health, vision, hearing, social and emotional status, general intelligence, academic performance, communicative status, and motor abilities" (Section 300.304(c)(4)).

Expanded Core Curriculum

Students with visual impairments require appropriate instruction in a wider variety of subjects than their typical peers and peers with other disabilities. In order to be educated effectively, students with visual impairments require assessment and instruction in all areas of the ECC (see Table 1) that apply to their potential abilities. Areas of the ECC include areas of instruction above and beyond the general curricula (Lueck & Dutton, 2015; Sapp & Hatlen, 2010). These areas include compensatory/access skills, sensory efficiency skills, assistive technology skills, O&M, independent living skills, social interaction skills, recreation and leisure skills, career education skills, and self-determination skills. All of these areas of assessment and instruction also apply to students with CVI because just as students with low or no vision do not learn incidentally from visual observations and modeling, students with visual processing disorders also have barriers to acquiring these skills (O’Brien & Martyn, 2015).

Table 1

The Expanded Core Curriculum

Expanded Core Area	Definition and Examples
Compensatory/access skills	Skills critical to access the general curriculum. Examples: concept development, communication modes (Braille, large print), organizational skills, accommodations
Social skills	Individuals who are visually impaired cannot learn social interaction skills in a causal and incidental fashion. They learn through sequential teaching and modeling. Examples: physical gestures, social integration
Recreation and leisure skills	Deliberately planned instruction should focus on development of lifelong skills. Examples: hobbies, sports, games, physical fitness
Assistive technology and technology skills	Provides access to the general learning environment. Examples: media literacy, technical concepts, appropriate assistive devices, information access
Orientation and mobility skills	Independent travel as a basic right to enable enjoyment and education from the environment. Examples: body image, travel, spatial awareness, safety, directionality, and navigation skills
Independent living skills	Independently performed tasks and functions. Students who are visually impaired need direct, sequential instruction to learn these skills. Examples: hygiene, food preparation and retrieval, money management, time monitoring, dressing
Career education	Explicit focus on exploring interests, areas of strength, job awareness, planning, preparation, placement, work ethic.
Sensory efficiency skills	Training students to use their remaining functional vision and tactile/auditory senses better and more efficiently. Examples: use of low vision devices, responding to environmental cues
Self-determination skills	Blind students need explicit instruction to develop sense of self, decision making, problem solving, goal setting, advocacy, self-control, assertiveness.

Note. Adapted from Lohmeier, 2009, Aligning state standards and the expanded core curriculum: Balancing the impact of the No Child Left Behind Act. *Journal of Visual Impairment & Blindness*, *103*(1), 44-47.

Cerebral Visual Impairment Specific Assessment

Lueck and Dutton (2015) recommended multidimensional assessments for students with CVI. These must consider both visual functions and functional vision. Visual functioning refers to the "performance of components of the visual system" (Bennett et al., 2019, p. 30). These are gathered from ophthalmological examination results. Functional vision refers to the abilities of the child to carry out typical and routine visual tasks. It is also necessary to identify the visual processing concerns related to the damage of the visual brain. This is most comprehensively done through reviewing the clinical results of brain imaging (when available) along with history-taking, observation, interviews, and performance on tasks. Motor function, social and emotional skills and behaviors, and auditory processing needs are also required to fully serve the student and meet their educational needs. The learning environment and other community settings must also be assessed to determine the influence of competing sensory stimuli and structural components (Lueck & Dutton, 2015). All assessment of students with CVI should be dynamic and on-going as students' abilities and needs change regularly according to any number of factors including academic and functional task demands, environmental changes, and health and energy levels or fatigue (Lueck & Dutton, 2015). Given the wide spectrum of information required, it is obvious that a collaborative, skilled team is necessary to understand the holistic needs of the child. For students with any type of visual impairment, parents have the most information to offer about their child and should be an integral part of the information-gathering process (Goodman & Wittenstein, 2003). The success of the child is largely dependent on meaningful involvement from the parents and other family members (Lewis & Allman, 2016).

The Cortical Visual Impairment Range

There are several tools to assist vision professionals when assessing students with CVI. Dr. Christine Roman's CVI Range tool takes into consideration the unique visual and behavioral traits of students with CVI (as cited in Newcomb, 2010). "The Range" (as it is usually referred to) relies on observations of a child's visual functioning behaviors as they relate to specific characteristics including color preference, need for movement, visual latency, visual field preferences, complexity, distance viewing, atypical visual reflexes, difficulty with novelty, and absence of a visually guided reach. Results are used to place children in phases of CVI (that are relevant to the categories of mild, moderate, and severe) and serve to provide access to the educational curriculum and the ECC. This tool is designed to provide both assessment and intervention.

While this tool has been reported by Newcomb (2010) as a reliable and valid assessment with a Cohen's kappa rating of .83 for interrater reliability (excellent agreement), the evidence base of it is limited. The additional published study on the effectiveness was published by the authors (Lantzy & Lantzy, 2010) of the CVI Range. The study looked at the etiologies of 73 children seen at the Pediatric View Clinic (a CVI-specific clinic) at Western Pennsylvania Hospital in Pittsburgh. The study did not report sample characteristics, recruitment, full results, or time between assessments. The results indicated that it took 3.7 years for children to move from the first phase of the range (severe) to the third phase (mild). It is difficult, as a researcher, to understand what variables were in place that allowed children to improve during this developmental period. One would assume the limitations are related to family intervention and support, additional therapeutic interventions, and the amount of stimuli children are exposed to or not exposed to during this period as well as associated neuroplasticity and changes in brain development.

Three-Tier Assessment Model

In their seminal text on the topic, *Vision and the Brain: Understanding Cerebral Visual Impairment in Children*, editors Lueck and Dutton (2015) offered a three-tier assessment process for this population. Salvia et al. (2016) defined assessment as “The process of collecting data for the purpose of (1) specifying or verifying problems and (2) making decisions about students” (p. 371). Children with any manifestation of CVI require multidimensional assessment. Lueck and Dutton (2015) recommended children with CVI be evaluated in each of the following areas: visual functions and functional vision, visual processing concerns, motor and verbal functions, social and emotional effects of the condition and behaviors, auditory processing, and evaluation of the environment and how it may affect the child’s performance. Again, these assessments are done by the various professionals who work with the student as collaboratively as possible.

The first tier of assessment focuses on assessment of vision, visual perception, and auditory screenings and observations of adaptive behaviors. This tier involves structured history-taking, family reports/interviews, reviewing medical and clinical records, and direct observations and screenings. Tier 2 considers the roles of dorsal and ventral stream dysfunctions and how they might manifest through direct observation and report of the child’s behavior. The concerns in this category are the higher order visual processing differences. For those children with functional vision, this tier looks more closely at their visual behaviors as they are related to ventral and dorsal stream dysfunctions (i.e., recognizing and labeling objects, wayfinding, dealing with visually complex scenes, etc.). See Figure 1 for more information. Visual perceptual testing might also be done at this tier of testing. Any tests performed must be matched to the child's cognitive abilities (Zihl & Dutton, 2016). The last tier of assessment looks at the child's performances in functional tasks/situations and very closely considers the impact of the environment on the child's learning. While this seems like a large undertaking for an educator, in terms of scheduling and efficiency, much of the information is gathered from resources already available within the child's records, and mostly all of the areas can be assessed in collaboration with other educational professionals. For students with multiple disabilities, families really must participate in all areas of assessment and evaluation. Families can help educators understand what is motivating to the child, subtle communication and learning styles, and transferring skills from the home and school setting (Lueck, 2004).

Insight/Visual Skills Inventory

The Insight/Visual Skills Inventory assessment was developed by Dutton and his team at the Glasgow Hospital for Sick Children (as cited in McCulloch et al., 2007). It is available in online, printable formats and can be used by TVIs and educators to probe visual behaviors and functions. It is useful because it can discern visual behaviors that standardized clinical assessments cannot. As noted above, it has been used successfully in a variety of clinical environments. Most recently, Tsirka et al. (2020) investigated the effectiveness of habilitation strategies specifically related to family responses derived from the results of the Insight/Visual Skills Inventory. The authors found correlations amongst the inventory, intelligence testing (Wechsler Intelligence Scale for Children, 4th edition) and visual motor (Beery-Buktenica Test of Visual-Motor Integration) and facial recognition (Benton Facial Recognition) tests, suggesting that it was an effective tool for discerning visual perceptual difficulties. This tool is useful for educators in that it facilitates the relationship between family and assessor/teacher as a requirement that will allow the educator to learn about the child from the person who knows them best. The literature has not yet provided evidence that the strategies developed from this tool are effective. Just as with the CVI Range assessment studies (Lantzy & Lantzy, 2010; Newcomb, 2010), it is difficult to parse out the variables involved that are the cause for improvement in children. However, both the Range (shortened from the CVI Range) and the Insight (shortened for the Insight/Visual Skills Inventory) provide families and practitioners with information about the child’s challenges with CVI and provide information on the next steps for educational and functional interventions. Further research must be done to show the information gleaned from these assessment results in strategies and interventions that play a significant role in a child’s progress.

Validity and Reliability

One of the issues when assessing and evaluating the abilities of students with visual impairments is establishing whether educational and psychological testing is a valid and reliable means of ascertaining their skill levels or abilities. Few tests are valid and reliable for students with ocular visual impairment; this is also true for students with CVI. It is also difficult to find personnel who have the unique set of skills necessary to assess these students (Goodman & Wittenstein, 2003). If tests that are considered valid are adapted for the visual needs of students, they could be rendered invalid because they have been altered. Careful attention must be paid to visual demands and visual-based questions and items on assessments (Lueck & Dutton, 2015; T. Pawletko, personal communication, March 7, 2020).

Educational Planning and Programming

Special Education Law and Students with Visual Impairment

Typical visual impairment is usually identified and diagnosed by an eye care specialist (ophthalmologist or optometrist) who will refer parents to services from a LEA or school district.

The diagnosis and/or clinical findings are used by the educational personnel to recommend the child's placement and learning needs (Lewis & Allman, 2016). Children with multiple impairments (who can also have a diagnosis of CVI) can be more difficult to assess (Lueck et al., 1999; Lueck & Dutton, 2015). These children can be more reliant on the TVI or educational specialists and are also at risk of being under identified (Fellinger et al., 2009; Van den Broek et al., 2006). Students with any type of visual impairment need their programming aligned with the appropriate learning media, the necessary accommodations for accessing their class materials and activities (based on assessments), and instruction in all areas of the ECC. Much of the evaluations for students with visual impairment and especially those with multiple disabilities involve careful observations in various environments and surveys and interviews completed by their family and teachers (when appropriate).

Student Rights

Like all children with disabilities, children with documented visual disabilities are to be guaranteed a FAPE and that the rights and protections of Part B of the IDEA are to be provided to children and their parents (Office of the Federal Register, 2000). Furthermore, the reauthorization of the IDEA Amendments of 1997, Public Law 105-17, clarified the responsibilities of public agencies in the education of students with visual impairments and blindness with respect to literacy instruction. (IDEA, 1997). The reauthorized statute provides that IEP teams are required to provide instruction in Braille, unless the IEP team makes the determination that it is not appropriate. The only way to make this determination is through the conduction of the previously discussed LMA.

To determine the appropriate reading and writing media, the TVI must base the recommendations on the "specific needs of individual students, as demonstrated by a thorough learning media assessment" (Spungin et al., 2007, p. 4). In addition to determining the media the child will use for literacy instruction, the team must also consider behavioral interventions, English language learning needs, communication needs (if the child is deaf and hard of hearing), and assistive technology devices and services (IDEA 34 CFR 300.346(a)(2)(v)(2004). Additional needs in all areas of the ECC also need to be considered as part of the IEP process to ensure that the student has appropriate access to the general curriculum.

Parent Participation

While the research reveals that a child's success in special education programming is largely dependent on the meaningful involvement of family members, it is not always the case that parent are equal partners in the IEP process (Drasgow et al., 2001; Fish, 2008; Fitzgerald & Watkins, 2006; Lytle & Bordin, 2001; Pruitt et al., 1998; Salas, 2004; Sheehey & Sheehey, 2007; Stoner et al., 2005). Family involvement in the IEP process is mandated by special education law. The IDEA amendments of 2004 strengthened the important role that family members play as part of a child's educational team and their inclusion through all phases of educational programming. From a legal standpoint, the emphasis on parent participation in IDEA is delineated in the federal system; IDEA Part B Indicator 8 states that states must report "percent of parents with a child receiving special education services who report that schools facilitated parent involvement as a means of improving services and results for children with disabilities" (20 U.S.C. §1416(a)(3)(A)). Even with this in place, research documenting parent input in assessments and IEP meetings is scarce.

A recent study conducted by Kurth et al. (2019) examined IEPs for parent involvement and found that parent priorities and concerns only translated into student goals and services two-thirds of the time. A case law (e.g., Doug C. v. Hawaii Department of Education, 720. F.3d 1038,

2012) that further confirmed the role of parent participation in the IEP decision-making process with a court finding that the parent was denied participation in his son’s IEP meeting because of scheduling conflicts. The judges found that parents both represent the best interests of their children during the IEP development process and provide critical information regarding their child to the team that only they know.

If the research in this area is scarce for children with disabilities, it is even scarcer for children with visual disabilities. In a 2003 study of 45 families of students with autism and blindness, Spann et al. (2003) found parents reported that their children’s IEPs were developed before they had input, and their ability to contribute to their child’s programming improved as their children aged and they became more comfortable with the special education process. In one of the only studies of this type including parents of children with visual impairments, Corn and Lusk (2018) conducted a survey of 192 parents of children with albinism. The parents could not provide information about the assessments their child received. It can be assumed this means that they were not asked to give input on any aspect of their child’s functioning, visual or otherwise. They also shared they did not receive information about their child’s reading levels or the services their child was receiving. Another issue this study revealed was that student needs in terms of the ECC were not being addressed. Their children were not receiving instruction in O&M, nor were they learning how to utilize low-vision devices and technology for learning. These are two vital areas of the ECC to access instruction and independence for students with albinism who traditionally have low or limited vision. Corn and Lusk (2018) concluded that there was a delay between the age of the children’s albinism diagnosis and the age at which their education services were first provided. They also concluded that families required more accurate information about the provisions of IDEA (2004), Section 504, and the Rehabilitation ACT of

1973 (Office for Civil Rights, 1986) and the impact of these laws when it comes to services for their children.

Collaboration with Families

Family involvement is “crucial to achieving a complete picture of a student who is visually impaired” (Goodman & Wittenstein, 2003, p. 46). It is recommended for all students with visual impairment that family interviews, skills observations in the home setting (when possible) and pre-assessment planning that starts the parent/teacher partnership all be integral parts of a comprehensive assessment process. This approach is vital for students with CVI because among the challenges children can have are those that are communicative—meaning that if a practitioner is new to them, they might need assistance in understanding the questions asked and expectations of the environment (Lueck & Dutton, 2015; Roman-Lantzy, 2007; Zihl & Dutton, 2016). Additionally, children with CVI have difficulty processing new or novel information in unfamiliar environments. To get the most accurate representation of a child’s skills, practitioners and clinicians must understand these barriers.

Recent research on parent knowledge and CVI (McDowell, 2020) sheds light on the needs of parents during the diagnostic process for their children with CVI. Parents need information in a format that is accessible and easy to understand at the time of their child’s diagnosis. McDowell found that parents develop confidence and advocacy skills when they are provided with information on CVI that is relevant to their child, and it also allows them to build collaborative relationships with the professionals supporting their child. Effective communication with both doctors and teachers is crucial for the parents and caregivers of children with CVI. Lupón et al. (2018) reviewed the existing literature on quality of life for parents of children with visual impairments. Understandably, parents are worried about their children’s future, but they are also concerned about school and the psychosocial aspects of fitting in, participating in leisure activities and the way others perceive their children, as well as issues on access and inclusion. Access and inclusion can only be achieved from the collaboration of families, educators, and staff for students with any disability. When parents are involved in the decision-making process, children show greater educational success (Stoner & Angell, 2006). Visual impairment affects the entire family system and requires acknowledging the perception of all members of the family (Lupón et al., 2018). Greater educational success is also facilitated by accurately building comprehensive assessment into specially designed instruction for students with CVI.

Educational Implications

Assessment leads to decision-making throughout the IEP process to develop goals and objectives, guide lesson development, and determine the intensity of instruction and intervention (Goodman & Wittenstein, 2003). For students with CVI, assessments must be an ongoing process, and approaches need to evolve as the child changes and grows (Lueck & Dutton, 2015). Using these methods, practitioners must develop interventions. Consistent interventions embedded throughout daily routines are the cornerstones of effective instruction for children with CVI (Lam et al., 2010; Smith et al., 2020; Zihl & Dutton, 2016). The most effective teaching interventions for this population combine clinical understanding of visual deficits, developmental understanding of the child’s abilities, and awareness and practical approaches to assist with missing, overwhelming, or unreliable information from the environment.

Learning Challenges

Each type of student with CVI, from those with severe multiple impairments to those who perform at an academic level, can demonstrate a wide variety of issues with learning. From perceptual learning from pre-semantic language development, to problem-solving to attention, motivation for learning, social and emotional needs, and executive functioning. In general, good teaching practices are integral to all students with CVI. Needs must be targeted and aligned with interventions that are specific to each child. Skills and behaviors must be taught directly (Lueck & Dutton, 2015; Zihl & Dutton, 2016) and consider the role that access to visual information plays in the development of information processing. Purposeful instruction must include sustained, consistent information over time and provide multiple opportunities for learning. Essentially, educators and interventionists must provide the support, structure, and sense-making that is not naturally occurring via typical information processing in this population.

The Need for Developmental Programming and Perceptual Learning

Children with a diagnosis of CVI need foundational skills purposely taught. Just as students with blindness and visual impairment have difficulty with incidental learning, students with CVI also have a myriad of barriers to information, experiences, and opportunities. In most cases of CVI, there is some residual vision. Some children with CVI may benefit from instruction in the use of basic visual skills and behaviors (Dennison & Lueck, 2006; Lantzy & Lantzy, 2010; Smith et al., 2020; Zihl & Dutton, 2016). This means that parents, caregivers, and educators must understand the child’s visual abilities and adapt materials so that they are visually accessible. Consistent, reliable, information that the child can access, and use allows access to perceptual abilities that the child can build upon. To process information, the brain must use the visual (iconic) memory store to build representations that can be stored and made use of in the future for conceptual learning and building schemas (Zihl & Dutton, 2016). Instruction that promotes the development of perceptual learning includes errorless learning and adapting instruction and communication to the child’s developmental level. Top-down, conceptually driven processing requires the individual learner bring expectations and past experiences to their approaches to tasks and learning. Using consistent, appropriate strategies affords the learner these abilities. Strategies used to integrate information processing can be promoted for success. Neural networks need to be able to produce the correct outputs to make sense of the information and build accurate representations. Each set of these connections must be organized before changes can occur (Loftus & Loftus, 1976). The strategies outlined in this section indicate the behaviors that must be included in our teaching repertoire to educate learners with CVI.

Building Attention

Learners with CVI can have difficulty with maintaining adequate levels of alertness (Smith et al., 1999), sustaining sufficient levels of attention, concentration, and capacity for divided attention (Zihl & Dutton, 2016). For students with CVI to build attentional capacity, discomfort must be minimized. It is important to note that even typically developing children are limited in their ability to process a lot of competing sensory information at the same time. Capacity is limited to the information that we need to attend to. An individual can only recall four to five items from a brief visual presentation (span of apprehension). We are all able to see more than we can recall (McLeod, 2008). It is important to understand the limitations of the typically developing brain when considering the adaptations for CVI. The typical brain cannot do anything with the information attended to until we have decided what the presentation of that information means. Before this information can be of any real value to us, it must be transferred out of iconic memory capacity and transferred elsewhere before meaning can be attached to it. For students with CVI, we must decrease the complexity of the visual environment. We must understand the demands of the task involved versus the complexity of the task and minimize as many distractions as possible. The fewer distractions, the better the outcomes and the greater the access to the information being presented as the goal of the activity or task (Lueck & Dutton, 2015; Roman-Lantzy, 2007; Zihl & Dutton, 2016). Essentially, what we want the student to pay attention to must be choreographed in a way that they can access it, attend to it, build on their meaning of it, and store it for later use and generalization. A large part of executing this in an efficient way is to provide the student with high-contrasting, motivating materials (Hyvärinen, 2000; Lueck & Dutton, 2015; Roman-Lantzy, 2007) and (through the results of collaborative assessment) present them in a way that provides the student with visual access.

Meaningful Instruction

The same principles of learning that build capacity for students with disabilities are also advantageous for students with CVI. Universal design for learning (UDL), differentiated instruction, diagnostic teaching, and functional and meaningful activities all provide access and teaching tools to address the needs of children with CVI (Lam et al., 2010; Lueck et al., 1999; Lueck & Dutton, 2015; Smith et al., 2020). Additionally, positive, trusting relationships with teachers and therapists must be established. Instruction must avoid insufficient demands of an already overtaxed sensory system. Consistent social signals, regardless of student performance (Zihl & Dutton, 2016), should affirm students are valued and respected as part of the teacher/learner dyad. Positive experiences such as these can help to build appropriate social skills (which can also be difficult for students with CVI) and pave the way for positive interactions during learning experiences.

Tasks must be pre-structured and organized so that information that belongs together is categorized and executed in sections that allow the students to build them into memory and apply meaning. As the educator sets the stage for the experience, the tasks must be functional and meaningful. Global detail must be established before local processing of more fine-grained details. The task or information must be recognized as meaningful (Zihl & Dutton, 2016). Students need the information generalized for them before they can actively do it themselves through their adaptations of information processing. When introducing and through initial concept introduction, tasks must be consistently presented in the same, repetitive way under equal conditions, then moved onto changing context and generalizations. The instructor must consistently confirm and reward with positive reinforcement and teaching of self-monitoring strategies. Additionally, in order to facilitate the storage and use of information for the student, the instructor must establish the relevance of the activity to the child's everyday routines and experiences so that the child can further understand the purpose of the learning (Zihl & Dutton, 2016).

Executive Functioning

Teaching to a child's developmental level is a useful approach in students with CVI. The cognitive levels of the learner must be understood so that instruction matches the child's abilities and learning can be scaffolded. Visual perceptual tasks should be simple and concrete to allow for the building of representations in terms of what the child can handle cognitively and then build upon. According to Zihl and Dutton (2016), complexity must be increased gradually, and instruction should support realistic self-assessment of visual capacities and visual performance which will build a solid basis for the development of self-regulation. The capacity to learn is not necessarily innate, and educators must help the child to build it.

Learning and Memory

Part of "training" the visual system to establish visual skills and be able to discriminate between visual stimuli is understanding what children will need to be able to learn at whatever developmental level they are currently at. Visually, they must fixate on a target, observe it, and study a visual stimulus or discriminate visual stimuli based on different features present. Essentially, educators and caregivers need to teach them to see. This means we need to focus on what information is necessary for the child to access and observe. We also need to provide the specific ways in which they are to explore and interact with objects, learning materials, and the environment. In a recent study, multiple disabilities researcher, Mildred (Millie) Smith and her research team (Smith et al., 2020) found routine-based instruction provided more appropriate and sustained object perception and interaction in children with visual impairments and multiple disabilities. The participants were both in the sensorimotor stage of development. The research team, encompassing the strategies previously mentioned, purposefully built constructs for the participants based on functional goals with clearly laid out steps, consistent teacher/learner interaction, and engagement criteria. The results were consistent engagement with objects that increased duration and frequency of object interaction. Students went from only exploring items or ignoring them to intentionally attending and participating in functional interaction (Smith et al., 2020).

Conclusion

Comprehensive, multi-faceted assessment that encourages and includes meaningful parent participation is crucial for the overall success of children with CVI. There is very little research done that has attempted to understand the experiences of the parents/caregivers of children with CVI and their perspectives on their child's clinical and educational journeys and the effectiveness of their special education programs. Research in effective assessment strategies for children with CVI (Ferziger et al., 2011; Gorrie et al., 2019; Macintyre-Beon, et al., 2012; Ortibus, Laenen, et al., 2011) shows that families are the most reliable resource in determining the skill levels and needs of their children. Families must act as experts and advocates and be honored as an integral part of their child’s planning and education.

While CVI-specific assessments are available, there is still a need to provide evidence that strategies and recommendations from those assessments are effective. Parents of children with CVI and other complex visual impairments are not always satisfied with professional services provided to their children, nor are they given comprehensive information about their child’s condition (Jackel, 2019; Jackel et al., 2010; Lupón et al., 2018). The purpose of this study was to examine whether the educational needs of students with CVI, as perceived by their parents and set forth by their clinical and educational documentation, are represented in their academic/functional goals and programming. The hope is that this work will shed light on parents’ understanding of their child’s unique diagnosis and their experiences with their child’s clinical and educational assessments as they are integrated into their educational programming.

CHAPTER III

RESEARCH METHODOLOGY

Introduction

The purpose of this qualitative multiple case study was to examine the educational programming of students with CVI to determine if their needs, as perceived by their mothers and set forth by their clinical and educational documentation, are represented in their academic/functional goals and programming. This study identified how educational services and supports match a student's CVI profile. This document was developed for each child based on evaluation results and coded and analyzed for CVI characteristics and academic and functional challenges related to sensory needs. This profile was created from the clinical and educational assessments that were consulted during the educational planning and implementation process (CVI profiles for each participant's child are presented in Chapter IV). This study illuminated the extent to which parents' reports coupled with their experience with their children in the clinic, can aid in the creation and implementation of education programming for students with CVI. Results of this study also revealed parent perceptions of methods for advocating and supporting their children with CVI and defined their roles as participating members of their child's educational team. It also highlighted the importance of opportunities for collaboration with parents and families of children with CVI. The following research questions helped to gain an understanding of family experiences.

Q1 What are the mothers' experiences of their child's special education programming and goals for meeting their CVI-specific needs?

Q2 How does the mother's understanding and knowledge of CVI contribute to the educational programming or services provided?

Q3 How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?

Theoretical Framework

The theoretical framework for this study was constructivism/interpretivism. Crotty (1998) identified the characteristics of constructivist inquiry; human beings construct meanings through their engagement with the world they are interpreting. Qualitative research relies on the views of participants. The basic making of meaning is always social, and it comes from our interactions with a human community. Qualitative research processes are carried out inductively; the inquirer generates meaning from the data collected (Crotty, 1998).

In a constructivist/interpretivist paradigm, thematic data analysis is applied to create broader structures, assumptions, and meanings that are theorized as the foundations of what is articulated in the resulting data (Braun & Clarke, 2006). Constructivism is an appropriate theoretical framework for this study because the basic tenet of constructivism is that reality is culturally, historically, and socially constructed (Bloomberg & Volpe, 2019; Lincoln & Guba, 1985; Lincoln et al., 2011). This research method investigates and understands social phenomena from a context-specific perspective. The context in this study are the physical, emotional, and social spaces that parents and caregivers exist in which shape their unique experiences as parents and caregivers to children with CVI. Lincoln and Guba (1985) stated that the methodological process of this inquiry is influenced by the researcher and the context in which the study is conducted.

As an individual who teaches children with CVI, I have developed subjective meanings and “truths” based on my personal experiences, and these have led to multiple meanings. These meanings are centered on my expectations for the “right” or “most comprehensive” means by which I believe students should be evaluated and educated based on years of reading literature, assessing and teaching students, and learning about CVI. These meanings are wholly constructed within the context I sought to understand from the experiences of my participants. I presented the proposed research questions above and generated meaning from the data collected from my participants.

Most of the literature on CVI is based on clinical and medical diagnoses and assessments. While the literature is rich in detailing brain imaging techniques, it is scarce in providing whether the educational assessment and practices used for CVI are considered effective according to the individuals who know the children best. A constructivist approach to the study of CVI permits the inclusion of the medical and clinical profiles of students with the reflections and experiences of the family who attend IEP meetings, provide input to educators and medical staff, and are ultimately responsible for their child’s success in all areas of life. Throughout the research process, I maintained field notes that documented my thoughts and perspectives. Through this I analyzed and constructed an ethical perspective on the participants’ experiences (Creswell, 2014).

Research Genre: Case Study

The methodology applied in this study was a multiple instrumental case study. According to Bloomberg and Volpe (2019), case study is an in-depth exploration from multiple perspectives that expresses the complexity of multiple phenomena. I investigated three cases bound together as a unit. These cases included the mothers of children who are diagnosed with CVI at the clinic and who received ongoing treatment and therapies there.

Just as children with CVI can be considered a puzzle and require that practitioners understand multiple elements to create a holistic picture, the case study focuses on the interplay of all variables in order to provide as comprehensive an understanding of the phenomenon as possible (Merriam, 1985). The goal of this type of research is to develop an understanding and deep insights that will inform professional practice, community or social action, or policy development (Bloomberg & Volpe, 2019). These multiple cases were used to examine the integration of information about each child's CVI diagnosis, assessment, and parent input into special educational programming at the children's schools. This method of inquiry is used when a researcher wants to compare, contrast, and synthesize multiple perspectives centering on the same issue (Bloomberg & Volpe, 2019). As data were gathered for each case in this study, it was analyzed within the case itself and then, once all data for all cases were gathered, they were analyzed across cases (this is expanded on in the Data Analysis section of this chapter). This method is also an appropriate choice when the researcher poses questions that seek to explain a contemporary circumstance over which the researcher has little or no control (Yin, 2018). The participants in this study represented a group of interest. This group provided an explanation of the circumstance investigated because their children see medical professionals and educational staff who conduct specific educational assessments and medical evaluations in a clinical setting. They then participate in an IEP and educational programming process in their local schools in a proximal geographic area.

Case study is both a methodology and an object of study itself (Creswell & Poth, 2018). I used one of the key proponents of case study methodology, "case study," which describes a phenomenon and the real-life context in which it occurs (Yin, 2018). This line of inquiry emerges within the interpretive/constructivist approach with the goal of explaining how common practices in specific places are connected to larger processes. Furthermore, case study lends itself to the interpretive/constructivist approach in that it attempts to capture the perspectives of multiple participants, allowing focus on their specific meanings which will illuminate the topic of study (Yin, 2018). For this study I sought to uncover how the clinical and education assessments conducted at the clinic and in the educational setting paired with family knowledge of CVI are connected to the decision-making processes for developing special education programming for these children. I also hoped to uncover information about the family experiences through these processes as participants existed in both of those constructs.

Further elaboration on case study as a research method proves its utility for the purposes of this project. Schramm (1971) explained the essence of a case study--that it attempts to shed light on decision(s): why they were made, how they were used, and what the outcomes were. This aligns with the evaluation and assessment process conducted in both an education and clinical setting and illuminates how that information is translated into outcomes for parental advocacy, input into educational programming, and ultimately, student success. A study protocol is shown in Table 2 and detailed in the subsequent section.

Table 2

Study Steps and Procedures

Step	Description/Data Collection	Research Question(s) Addressed
1. Participant recruitment	Purposeful selection based on group selected by clinic staff	
2. Semi-structured interviews	Interviewed family on their experiences with clinical and academic assessment and educational programming process for their child with CVI *Data:* Responses coded thematically, using within case and across cases analysis	2. How does family understanding and knowledge of CVI contribute to educational programming or services provided? 3. What are family experiences of their child's educational programming and goals for meeting their needs in terms of CVI?
3. Review of clinical evaluations and assessments performed at the clinic.	Retrospective clinical examination results shared via DTA between the clinic's hospital and UNC Office of Research and Sponsored Programs *Data:* CVI profiles developed for each child based on evaluation results and coded and analyzed for CVI characteristics and academic and functional challenges related to sensory needs	1. How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?
4. Review special education programming documentation	Reviewed IEP or 504 Plans for eligibility, assessment information, recommendations for services, service providers, goals and objectives, supplementary aids and services and testing accommodations and modifications. Vision specific educational assessments (FVA, LMA, and CVI related). *Data:* Coding and thematic analysis of educational information compared within cases and across cases	1. How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?
5. Follow-up interviews	If needed, for clarification, confirmation, or missing information as each child's data is reviewed and analyzed *Data:* Responses coded and analyzed thematically	2. How does family understanding and knowledge of CVI contribute to educational programming or services provided? 3. What are family experiences of their child's educational programming and goals for meeting their needs in terms of CVI?

Collaboration with Hospital

This study was conducted in collaboration with a children's hospital located in a major city in the midwestern United States. Their pediatric ophthalmology department serves children with CVI in their specialty clinic. They screen patients for CVI, and if its determined they are candidates for further assessment, they are sent to the clinic for further diagnosis, assessment, and treatment. The clinic's staff is motivated to work with outside entities who share the same goal of furthering the clinical and educational best practices for individuals with CVI. Because the clinical research coordinator and staff at the clinic were interested in developing effective protocols and establishing relationships with individuals and organizations who work in the area of CVI, a partnership was formed from conversations at an international CVI workgroup meeting in the summer of 2019. The clinic has regular CVI clinics and a large pool of patients, who all undergo a standard of care related to their CVI. The participants are the family members responsible for their child's education, health, and well-being.

Once approval was received from the University of Northern Colorado (UNC) Institutional Review Board (IRB), an additional protocol developed specifically for the hospital clinic's Institutional Review Board was submitted as well. Due to the nature of patient recruitment and data sharing with the hospital, the hospital required a separate IRB process to ensure the study met research hospital protocols. The hospital IRB included a pediatric ophthalmologist from the department as the Lead Site Investigator and the clinical research coordinator as the lead point of contact for the study. All data were collected with the assistance of the clinical research coordinator. The clinical research coordinator recruited participants through administration of the demographic survey (Appendix B). The IRB approval process was lengthy. Multiple conversations were had by the hospital staff and my UNC advisor and research compliance officer to ensure the study was conducted in a way that protected the participants and mutually benefitted both parties. Once approval was received from the clinic's hospital research department, participant recruitment began.

Participants

In a multiple case study, individual cases must share a common condition and be categorically bound together (Merriam, 2009). Three family members of children with a diagnosis of CVI who have also been treated at the clinic comprised the participants in this multiple case study. The clinic was chosen after the researcher worked with the doctors and research coordinator at a national workgroup on CVI.

Individuals recruited for this study have participated in a minimum of two special education meetings for their child with a diagnosis of CVI prior to the study. The participants' children were enrolled in a school within the geographic area served by the clinic. Desired participants were the parents or guardians of children with a diagnosis of CVI and who were patients at the clinic. Specifically, these children presented with "moderate" to "mild" CVI and did not have severe, multiple impairments. This exclusion was due to the added complexity of special education programming and assessment of students with CVI and severe disabilities. Additionally, children must have exited out of early intervention services and were elementary-aged so that participants had some experiences with special education planning. Participants' children attended different schools within the hospital's geographic area. This allowed for a wider breadth of experience of the participants and a richer cross-case analysis. Descriptive statistics outlined the profiles of each child and included: age, gender, grade level, disability, location, and range/category of CVI according to clinic evaluation results. The severity of each child's CVI is based upon their score on the Roman-Lantzy (2007) CVI Range (as determined by the clinic physicians) and the following definitions developed by Lueck and Dutton (2015): (a) “children with CVI who have functionally useful vision and cognitive challenges,” and (b) “children with CVI who have functionally useful vision and who work at or near the expected academic level for their age group” (p. 14).

The participants in this study represented a purposeful sample. The selected unit of analysis for this study assumed they represented a group from which the most could be learned and lead to discovery, understanding, and insight. This method of sampling is widely used in qualitative research (Merriam, 2009) and is especially useful for a low-incidence population such as the one with a CVI diagnosis.

The clinical research coordinator at the clinic assisted with the recruitment process. She ensured that participants met study criteria; then the Lead Site Investigator (a pediatric ophthalmologist at the clinic) reviewed the selections and approved them. Participants were recruited based on the retrospective data gathered from the clinic. In multiple case study research, each case must be carefully selected so that the cases will elicit similar results or “predict contrasting results but for anticipatable reasons (Yin, 2018, p. 91). The goal, then, was to choose a small number of cases that could be analyzed within themselves and across one another through the recruitment of participants who all had the same clinical experiences and had participated in the educational planning for their children with similar etiologies and visual conditions.

Each participant answered the demographic survey questions during a phone call with the clinical research coordinator. Originally, the survey was to be answered electronically, but clinic staff and I decided that conducting the survey via phone call would ensure more privacy than a shared online form. This survey included demographic information such as contact, ethnicity, gender, and child information such as age, grade, age of diagnosis, and details on special education services and participation in special education for their child. That information was used to include or preclude participants from the study. Selected potential participants were provided information about the study. Family members who expressed an interest in the study were given a copy of the informed consent form to read. Because the informed consent process was conducted remotely, a waiver of written documentation of consent was requested and granted. Study staff also provided all participants with a copy of the informed consent form via email or postal mail and answered all questions prior to documenting verbal informed consent/parental permission in the study record.

Three participants were selected for this study. Two additional participants who also met the inclusion criteria were chosen as back-up in case of attrition.

Data Collection

Once Institutional Review Board (IRB) approval was granted and participants were gathered, data collection began. Drafts of both the UNC IRB approval and hospital protocol approval can be found in Appendix J and Appendix K, and more detailed information on the data collection practices are below. The clinical research supervisor at the clinic’s Division of Pediatric Ophthalmology worked with the Research Compliance Manager at the University of Northern Colorado’s Office of Research and Sponsored Programs to implement the data user agreement (DUA) which ensured the confidentiality and protection of participant information. This agreement’s primary function was to protect the transfer of the retrospective records gathered from the clinic. The DUA allowed the clinic to share sensitive information with my institution.

Participants were chosen based on their responses to the survey and their ability to participate. Once participants were recruited and verified as meeting the inclusion criteria and consented to the project, the clinical research coordinator shared the survey responses via encrypted email messages. Once received, I followed up via email to schedule a voice call interview or video interview via the Zoom virtual meeting platform. The research assistant was present for the interviews as a representative of the children's hospital ophthalmology department in case the participants had any questions or concerns.

Retrospective records including eye report summaries and CVI-related assessments from the children's hospital clinic were shared via the DUA when the interviews were completed. The child's educational documentation including CVI and vision-related assessments such as LMAs and Functional Vision Assessments FVAs, and IEPs were requested during the interview as well as in a follow-up email reminder after the interview was completed. Participants emailed all records of interest to the clinical research coordinator at the clinic who then redacted the personal information, encrypted the documents, and sent them via email. I requested that the child's identifying information be redacted before it was sent. All data collected were kept on a password-protected laptop. Additionally, data were backed up on the cloud using the Microsoft platform OneDrive and, on a password-protected external hard drive.

In-depth interviews were conducted with each participant. Interviews allow the researcher to search across data sets to find repeated patterns of meanings (Braun & Clarke, 2006). They also allow the researcher to "build the intensive, thick description of a case study" (Merriam, 1985, p. 206). Interviews were recorded using the online virtual meeting platform Zoom. Each interview's audio and video files were downloaded from the cloud. The interviews were transcribed after they were conducted using Zoom's built-in transcription feature.

Transcriptions were checked for accuracy and kept on a password-protected computer in the researcher's home office. Transcriptions and audio recordings were erased after completion of the study. Self-selected pseudonyms were used for the participants in this study to protect their privacy and keep information confidential. If the participant's did not choose a pseudonym, one was assigned to them.

Researcher as an Instrument

Case study research is not an easy task for the researcher. According to Yin (2018), this manner of research makes demands of your intellect, emotions, and ego because the work is a constant process of continuous interaction between the research topic studied and the data being collected. For me, the topic of CVI is highly internalized; it is the reason I am pursuing my doctorate degree because at every turn of the page and every moment of instruction, there is a very real desire to learn more and do better. A major facet of qualitative research (Creswell, 2014) is that the researcher is involved in a prolonged and intense experience with the participants. The researcher must reflexively identify biases, values, and personal background (Creswell, 2014) and other personal and unique factors that will shape the interpretations formed during a study.

Previously, I stated my relationship with CVI and demonstrated, through the literature, that the ultimate goal of educational programming for this population should integrate objective clinical information with subjective and objective educational assessment and report. This intersection is a valid approach for all children with disabilities--to understand how disability impacts learning. But, in the field of blindness and visual impairment, we must consider clinical information as part of a learning program. This study allowed me to further evaluate the relationships between clinical and educational evaluation, programming, and outcomes for learning. I am most interested in what I learned from the participants' experiences with their child's educational journeys and their roles within them. Every effort was made to maintain objectivity at every level of data collection and analysis; however, I must acknowledge my existing values and beliefs as part of this stance. To mitigate bias, I had no previous knowledge of the participants' experiences in the clinical or educational setting, except for a general idea of the assessments conducted on their children that was provided by the clinic's Lead Site Investigator. I also kept a journal or field notes during each step of the study which served to keep my research process transparent and reveal any past experiences and assumptions related to the data collected (Ortlipp, 2008). My stance as a researcher included the foundational beliefs that the participants had something of value to contribute from worthy experiences and that their opinions were of interest to me for the advancement of my research questions (Merriam, 2009). In case study research, it was imperative that the researcher be open to contrary evidence when it arises in the data. This also serves to test potential bias (Yin, 2018). Additionally, interview questions administered to participants were open-ended and semi-structured and did not contain leading questions. Yin (2018) wrote that case study interviews need the researcher to operate on two levels at the same time, "verbalizing your actual questions in an unbiased manner that serves the needs of your line of inquiry . . . while simultaneously putting forth friendly, nonthreatening, but also relevant questions" (p. 161).

For this study, interviews were the primary interaction between researcher and participant. Yin (2018) outlined desired characteristics for the case study researcher when collecting evidence. These include being prepared to make judgment calls with care and minimal bias, asking good questions, being a good listener, staying adaptive, having a good grasp on the topic of study, and conducting research ethically. As a researcher, I adhered to these attributes as strictly as possible and developed them where I saw a need to build my skills as a researcher and interviewer.

Interviews

Interviews were conducted via Zoom during a password-protected session. These commonly used platforms allow participants to remain in their own environment while responding to questions and provide a convenient way to communicate when face-to-face interaction is unavailable, provided there is a good internet connection (Braun et al., 2017). Interviews were recorded with the participant's explicit consent which was requested at the start of the interview. Interviews were conducted once and were between 75 and 90 minutes long. Semi-structured interviews allow the researcher to respond to the topic studied in real-time and attend to the emerging worldview of the respondent (Merriam, 2009). The researcher can respond to new ideas on the topic and record responses as information emerges from participants. In order to create a rich dialogue with the participants and the evidence they present, the researcher must continually question "why events and perceptions appear as they do" (Yin, 2018, p. 121) and evaluate personal responses as the inquiry proceeds.

At the start of the interview, neutral, descriptive information was requested to lay the foundation for questions that got to the interviewee's opinions, values, and perspectives on the topic explored (Merriam, 2009). Once introductions were completed and demographic information was confirmed, the interview was conducted. Interview questions (Appendix G) were developed to gain insight into the mother's experiences and knowledge gained from their child's clinical evaluations at the clinic, their role in their child's special education meetings and assessments, and their knowledge of how the information from both clinical and educational assessments are integrated into their child's educational programming. A follow-up interview was conducted, when necessary, to clarify information, confirm understandings, and ask questions as they emerged from the data collected. This included any clarifications required that arose from the educational or clinical documentation that the family did not address in the first interview.

Documentation

In qualitative research, “documentation” is an umbrella term that encompasses all the digital and physical material relevant to the study at hand (Merriam, 2009). Merriam (2009) also pointed out that there are two questions the researcher must ask when determining whether the use of documentation is appropriate. First, do the documents give insights or information relevant to the research? Secondly, can the documents be gathered in a practical and reasonable manner? Pondering these questions, the answer was an unequivocal and emphatic “Yes!” It is also advantageous to include documents as data because they can verify emerging hypotheses, advance new categories, offer historical understandings, are stable and grounded in the real world, and do not change (Merriam, 2009). A flowchart showing data collection steps for interviews and document analysis is provided in Appendix H.

Documents can be considered “symbolic materials” and aid the research in providing pre-existing information and things that have taken place before the research begins (LeCompte & Millroy, 1992). Documents used in this study are explained in detail below. Additionally, a reflective journal was kept throughout the research process. In this journal, I documented my research process and practices which enabled me to reflect critically on those elements as I conducted my research (Ortlipp, 2008). Using the children’s visual and educational documentation, I generated documents after the start of the study and conduction of interviews to determine their quick-reference CVI profile. I developed these profiles by carefully looking at the child’s vision diagnosis, visual functioning, and abilities to create a holistic profile and a readily available document to use as data, both within and across cases. As the primary research instrument, I relied on my skills and intuition to find and interpret the data from the documents collected for this study (Merriam, 2009). These profiles included information taken from the educational (outlined below) and previously mentioned clinical documentation. The demographic information collected by the clinical research coordinator also served as documentation for the study and is included to discern information about the students, though names were not used, and pseudonyms were chosen by participants or myself if the participants did not have a preference.

Clinical Documentation

At the Pediatric Ophthalmology Clinic, children with a suspected diagnosis of CVI are chosen based on a few factors. They must have a medical history consistent with injury to the post-chiasmatic visual pathways such as perinatal hypoxia, brain hemorrhage, or bacterial brain infection. Practitioners might use screening questionnaires, and a complete eye exam is performed for each patient. These exams include visual acuity measurements, visual fields, eye movements and alignment, refraction and examination and dilation of the fundus, and contrast sensitivity. If there is a decreased visual response and the eyes appear normal, the diagnosis is made. Children are then referred on to a CVI specialty clinic for further assessment (K. Castleberry, personal communication, August 4, 2020). The clinical documentation gathered during these appointments and clinics was available retrospectively for the purposes of this study and shared according to the DUA between the two organizations. This documentation included optometry and ophthalmological reports and summaries, The CVI Range Assessment (Roman-Lantzy, 2007), additional screenings, and any additional CVI-specific evaluations or assessments conducted in the clinic. Participants were chosen based on their responses to the introductory demographic form and their willingness to participate in the study. Neither the clinical nor educational documentation was reviewed until after the initial interviews were conducted. More information on this is included in the Credibility and Trustworthiness section below.

Educational Documentation

In case study research, each data source is considered its own unique phenomenon and contributes to the larger construction or phenomenon as it develops (Bloomberg & Volpe, 2019). Educational documentation was requested after participants were recruited and had completed the interviews. The clinical research coordinator redacted identifying information and provided the participant's child's IEP. The IEP serves as the blueprint for a student's special education program and ensures that the child's disability is legally identified and that they are receiving the specialized instruction or related services required so they may compete on an equal basis with their typical peers. Accompanying vision-related educational assessments were also reviewed. These included a FVA of the student's visual skills. The FVA (conducted by a certified TVI) relays important information to the team about the student's visual functioning and background information about their vision diagnosis and history. Another important element of an evaluation for a child with visual impairments is an LMA. The LMA is an "objective process of systematically selecting learning and literacy media for students with visual impairments . . . regardless of level of vision or severity of additional disabilities" (Koenig & Holbrook, 1995, p. 17). This assessment allows the TVI to discern the student's most efficient sensory channel or channels that they will use to access literacy learning and provide a basis for instruction. Best practice calls for the inclusion of LMAs as part of assessment of students with visual impairment and amendments to the IDEA (2004), mandate that students be provided instruction in braille, unless the educational team decides braille is not appropriate. The LMA provides the assessment from which the vision professional makes that decision. In general, children with CVI are not necessarily braille learners, unless it is deemed, they have significant enough acuity loss. Learning media assessments or any information from them was not found in the documentation provided by the mothers in this study (this topic will be addressed more in the discussion section of the paper).

Also reviewed were CVI-specific assessments performed by school or local education agency-employed vision professionals (and are in addition to the evaluations performed at the children's hospital clinic). Relevant information was taken from educational documents and added to each child's CVI profile (Appendix G). This profile served as an easily accessible, graphic representation for keeping student data organized. The purpose of the CVI profiles was that they can be used as a quick reference. I am not the first person in the field of serving children with CVI to use a profile-type tool (Hyvärinen & Jacob, 2011; Lueck & Dutton, 2015; McDowell, 2021). For the purposes of this study, it was helpful to organize the information of children with medical histories that were complex. While none of these children had severe, multiple disabilities, due to complex histories in early childhood as well as prematurity (in two cases), their young lives are already full of many clinical experiences. Tools such as this one can allow one to see patterns that link the severity of CVI (or the phase) with contributing diagnoses and functional challenges. They are also useful to other practitioners when trying to communicate needs to teams and serve as helpful visual reminders.

The information used to put together these profiles is taken from the eye doctor reports, functional assessments of the child's vision, the CVI Range tool and the Dutton Questionnaire. Keep in mind that the CVI Range tool and the Dutton Questionnaire (more notably) are interviews of the parents. The assessor also does one-on-one assessment with various materials for the CVI Range. It is important to note that parent input is a large part of these assessments as parents know their child best and have seen how they interact with the world at large, not just in a doctor's office.

Reflective Journals

During the interview process, I had the opportunity to maintain a journal. In qualitative research, data analysis should be done in conjunction with data collection (Merriam, 2009). Keeping a journal enabled me to collect the data while experiencing the dynamic between researcher and participant. Maintaining a reflective journal does not control bias in a qualitative study, but it renders bias visible to the reader (Ortlipp, 2008). Because the interviews for this study were my initial data set, I both recorded them and took notes as participant experiences emerged and developed. As the participants provided insights through conversation and their responses to questions, my own responses and thoughts were reflected through the journaling process. This also allowed me to pose questions that I was able to return to upon completion of the documentation reviews. Journaling also aided in chronological organization of personal thoughts and theories generated throughout the research process.

Data Analysis

One strength of conducting a descriptive qualitative case study is the variety of methods used to weave together strands of data to tell a story about students, families, and their experience with visual disability in a visually constructed world. Data analysis for the interview portion of the proposed study was thematic in nature. Thematic analysis is not a system that encourages generalizations beyond cases but offers a rich description of the case in order to understand its complexity (Braun & Clarke, 2006). The goal for data analysis is "transferability" which will clarify “how (if at all) and in what ways knowledge and understanding can be applied in other contexts, settings, and conditions (Braun & Clarke, 2006, p. 51). I attempted to address the issues of transferability through my presentation of thick, rich description. This approach established the case studies and revealed their potential application to ultimately reach a broader context to potentially inform practice or policy.

In order to conduct a multiple-case study thematic analysis, it is necessary to analyze data within cases initially and then across cases as data are compiled. There are advantages to this multiple-case study approach. According to Yin (2018), evidence arising from multiple cases is often more compelling and the design is considered more robust. I started with the three case studies and showed how each participant’s experience as a parent/caregiver and advocate of their child in the clinical setting is shaped by their experiences in the educational setting. The cases should persuade the reader of a general construct about the story of each case and then, the cases across one another. Each case was analyzed within itself using the six steps of thematic analysis developed by Braun and Clarke (2006). They included the following steps: (1) familiarizing with the data, (2) generating initial codes, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report. Subsequently, once cases were analyzed within cases, they were analyzed across cases using the same technique. Table 3 shows how I followed each of the six phases and the actions I took to analyze the data during each phase.

Table 3

Action Steps for Analysis

Phase	My Action in Each Phase
1. Familiarize yourself with the data	Immersed myself in the data so that I was familiar with the depth and breadth of the content through repeated and active reading and began taking notes for later coding.
2. Generate initial codes	Produced initial codes from the data, organizing data into initial groups, and worked systematically through the entire data set.
3. Searching for themes	Worked to refocus data at the broader level of each theme and sorted codes into potential themes.
4. Reviewing themes	Refined the themes so that they were clear and distinguished between themes to determine what belonged together and what did and did not fit.
5. Defining and naming	Defined and further refined and established the essence of each theme and determined what aspects of the data it captured. Identified the story that each theme told and started considering official names for the themes.
6. Producing the report	Established the final themes and presented the story of the data, building a narrative to support the story that provides a complete picture relevant to my research questions.

Note. Adapted from Braun and Clarke's (2006) Six Phases of Thematic Analysis.

As the goal of analysis is to make sense of the data, Merriam (2009) reminds us that data analysis is really the process used to answer the research questions. The initial phase of my study was conducting the interviews, taking notes, and recording and transcribing the interviews, then taking notes again when re-reading and re-watching the interviews for any missed information or additional insights or questions. The recorded, transcribed interviews were reviewed for accuracy and analysis. To effectively analyze, during this first phase I familiarized myself with the data and established comfort with the methods established for conducting the interviews. I then identified segments of the first data set from the interviews, my notes, and journal, and judged their responsiveness to my initial research questions and the topic. This process involved generating initial themes or categories built from the data. All data analysis was done in conjunction with data collection (Merriam, 2009).

Once the interviews were conducted and reviewed and the educational documentation was received, I began my second phase of analysis by creating a database of the clinical information for each participant. This allowed me to be organize and familiarize myself with the clinical and educational document data through the creation of the CVI profiles within each case and record my thoughts and notes in the IEPs and other documentation. Additionally, I kept a separate notebook for information gathered from the clinic on visual functioning and any other information of note including acuity, additional disability, and other pertinent, gathered information. I actively reviewed the clinical assessments and the educational documentation for comparisons and contrasts. During data analysis, I took notes in the margins of documents and wrote memos to myself to capture reflections, tentative themes, hunches, and future pursuits (Merriam, 2009). I purposefully did not review the student’s clinical or educational documentation before the interviews. To conduct this study with as much credibility as possible, it was important to address bias. Because of my knowledge on the topic and personal and professional experience, I worked to confront bias by not reviewing any of the documents before conducting the interviews. This prohibited me from forming assumptions and ideas about the student’s needs and how they should or should not be addressed. Without previous exposure to this information, the participant was able to share their experiences and I was able to listen without any preconceived notions about their child or their child’s educational programming. I also stated this element at the start of each interview so that the participants understood that I have clarified my biases up front (Bloomberg & Volpe, 2019).

In case study research, data analysis requires bringing all the information about the case together. It is vital that the data are organized so that they are easily retrievable, and the researcher does not feel overwhelmed. The researcher must be able to locate everything during the analysis (Merriam, 2009). A case study database was constructed for each case. This consisted of recordings and transcripts of the interviews, field notes, documents, and a journal. Once the interviews were complete and the clinical and educational documentation gathered, all documents were kept in the database along with the child's quick-reference CVI profile.

During Phase 3, in collaboration with my peer reviewer, I distinguished significant statements from the interviews that related to the significant categories or topics of the research questions and established codes related to experiences during clinical and educational assessment, personal knowledge about the CVI diagnosis, the level of input in their child's educational programming, and reflections on how their child's needs were being met. The peer coder was a colleague who also studies low-incidence visual disabilities and interventions for students with blindness and visual impairment and has experience with qualitative research. With the help of my peer reviewer, I generated a list of potential codes based upon the detailed coding from the initial interviews.

After initial coding was established for the first interview, I coded the remaining data from interviews, using the computer-assisted qualitative data analysis software Dedoose. Dedoose is a cross-platform application meaning that it can be used across PCs, laptops, tablets, and phones, with each device granted the same level of access for working and collaboration. Dedoose is used to organize and analyze qualitative and mixed-methods research data and uses multimedia tools for data analysis and results (dedoose.com). Dedoose was a useful tool to assist me in organizing excerpts from the interviews and assigning categories for coding. For Phase 4, I reviewed the themes with my peer reviewer to jointly determine final themes. These were organized interactionally and used to generate a thematic map of the subsequent analysis (Braun & Clarke, 2006). During Phase 5, we formally defined and named the themes and determined how the analysis performed and how, up until this point, it told the story of the experiences of the parents/caregivers and their children. Finally, in Phase 6, once all themes and the narrative were established, my peer reviewer read the final draft and checked for inconsistencies and overall presentation of the data.

Clinical assessments, diagnostic screenings, and examination results were also analyzed for this study. These de-identified documents were analyzed using conventional content analysis as opposed to thematic analysis because the coding categories were derived directly from the text data (Hsieh & Shannon, 2005). The data from these documents consisted of each child’s placement on the CVI Range (Roman-Lantzy, 2007) and their specific visual challenges and abilities as well as ophthalmological reports and summaries. Clinical terms and language derived from these documents and assessments were used to build a complete picture of the child. Each child’s documentation was analyzed within the case to create a comprehensive picture of their visual challenges, abilities, and diagnoses. The cases were also analyzed across cases to compare the outcomes from the special educational programs. Retrospective information was organized by child (de-identified in the database) and visual functioning information, and CVI-specific information was merged into the child’s CVI profile quick-reference document. Notations were made regarding the level of information given to the clinicians by parents for the assessments and any other items of note were recorded.

Content analysis was conducted on the student’s most recent IEP and educational assessments (if available) provided to the clinical research coordinator via email from the participants following the initial interviews. This analysis was conducted in the same manner as the clinical documentation. Many times, these assessments are integrated directly into the educational paperwork, but some of the participants also had their own copies. This documentation was coded separately and analyzed for categories and themes that contributed to knowledge of the research questions. First, I read the parent input sections and noted instances (within the margins) of parent input on their child's visual functioning, needs, abilities, and any language about vision. I read the entire IEP initially and recorded my first impressions. I then went back and revisited any evaluation information inputted where the child's vision was concerned and any vision-related goals, professionals, service time, present levels of performance, and vision-related accommodations and modifications and coded for these items. This allowed for the categories and names to develop and flow from the data (Hsieh & Shannon, 2005). My peer reviewer coded concurrently. We independently coded initially and then met to discuss themes, agreements, and disagreements. Any functional and present-level information on the child's visual abilities was merged into the CVI profile. The documentation was analyzed within case first and then across cases once all the documents were collected and CVI profiles developed to create a rich, detailed description of the sample. All this information was kept in a password-protected laptop and backed up on a password-protected external hard drive as part of the digital case study database. Each parent, practitioner, and the researcher exist within their professional and personal constructs. Each one brings their interpretation to the patient through their work with the child and their experiences. In Figure 3, the outer ring represents the interpretivist conceptual framework. Inner stars represent within-case analysis, and outer stars represent across-case analysis.

Credibility and Trustworthiness

In case study, it is crucial that one determines the right balance of description and analysis when it is time to present the results. It is important to note that in thematic analysis, the themes come from the researcher's brain and are, therefore, a product of the researcher's experiences. The researcher plays an active role as the one identifying the themes and patterns and making the selections that will be reported in the results (Taylor & Ussher, 2001). Trustworthiness in a qualitative study increases its validity and credibility. Furthermore, to enact change within a field, the study must be rigorously conducted with insights and conclusions that connect with readers and practitioners (Merriam, 2009). Findings and results will only make sense if they are detailed enough and present the reader with an accurate depiction of the topic (Firestone, 1987).

Minimization of bias was a key way to establish my study as a reliable description and analysis of the topic. As explained previously, my past and current experiences as a practitioner in the field of visual impairments have shaped this inquiry from the start. However, I do believe there were safeguards in place to ensure credibility for this study. One intentional method was that I did not review any clinical or educational documentation prior to conducting the participant interviews. Because of my experience in providing instructional support for students with CVI, I did not want to bring any bias into the interviews regarding how these children should and should not be instructed or what was or was not appropriate for their education programs. I wanted a clean slate from which to learn about the children from their parents or caregivers directly prior to reviewing any additional information about the children. Knowing the child's clinical and diagnostic history would create an immediate bias. If questions arose as I reviewed the data, I followed up with the participants (see Member Checking section below).

By establishing a case database, I ensured that data were organized and protected. Also, the creation of a case study database increased the reliability of the study (Yin, 2018) because any interested reader could investigate the database. I kept a reflective journal (Bloomberg & Volpe, 2019) throughout the study for personal notes and insights and to keep chronological order of the data collection and analysis. This allows the reader to understand my underlying thoughts, processes, and decision making. It also provides the ongoing critical reflection and reflexivity for the study which provides the reader a chance to assess the trustworthiness of the study's findings (Bloomberg & Volpe, 2019). Additionally, five credibility measures were employed: (1) triangulation, (2) rival checking, (3) peer reviewing, (4) member checks, and (5) bridling.

Triangulation

In qualitative research, triangulation attempts to obtain an in-depth understanding of the phenomenon under study. It adds rigor and depth to the study and provides corroborative evidence of the data obtained (Bloomberg & Volpe, 2019). Establishing validity is a goal, not a product, of research, and it is assessed relative to the purposes and circumstances of the research (Merriam, 2009). Triangulation is used to describe the multiple methods of data collection used relevant to the phenomenon of interest (Merriam, 2009). The ability to use multiple sources of data is a major strength of case study research (Yin, 2018). Using multiple documents (demographic survey, reflexive journal, educational planning assessment and documents, transcribed interviews, and clinical and educational assessments), I developed a comprehensive understanding of the parents' experiences within the clinical and educational contexts of the study. Using multiple sources of data provided me with the opportunity to develop "converging lines of inquiry" (Yin, 2018, p. 172). These case studies are more convincing and accurate because I used all the sources at my disposal and provided by the clinic, parents, and myself to develop a point of convergence. Yin (2018) maintained that to establish construct validity for a case study, one must use multiple evidence sources and use colleagues and peers to review drafts of the case study reports. Triangulating data and using my peer reviewer, who is also familiar with CVI and the challenges of visual impairments, was utilized.

Rival Checking

In case study research, rival explanations of evidence are useful for further establishing the credibility of the work. “Plausible Rival Hypotheses” (Yin, 2018, p. 13) are presented as implications of what the data are telling us that might be an alternative explanation or interpretation to what we seek. Rival checking helps us to achieve a level of statistical relevance and establishes criterion for understanding the strength of the findings (Yin, 2018). Through exploring rival explanations, the researcher engages in a systematic search for alternate themes and divergent patterns (Patton, 2001). As part of this process, I reflexively presented my current and standing biases on the topic. I acknowledged my current predispositions and presented the value of these perspectives. In the final report, I demonstrated the rival explanations examined by reporting my systematic search for alternative ways of understanding the study and data collected (Crabtree, 2006).

Peer Reviewing

Peer reviewing is an additional check to establish an external check on the credibility of a qualitative study (Creswell, 2014). As previously mentioned, the peer reviewer was an individual in the same field of study with knowledge of the topic and who was also conducting research in the field of education of students with blindness and visual impairments. This peer reviewer was simultaneously conducting multiple studies in the field. The peer reviewer and I worked collaboratively on coding for thematic analysis of data. Peer debriefing was also used (Creswell, 2014) to ensure that the account made sense to other researchers. This adds validity to the results because it adds validity to the interpretation of data. I also called upon selected members of my committee to serve as another form of review for the study as it progressed.

Member Checking

Member checking is a way to solicit feedback on emerging findings to ensure that the researcher is not misinterpreting them (Merriam, 2009). Member checking helped to determine the accuracy of the findings because it is a process of presenting the findings to the participants and determining if the participants felt they were accurate representations of their experiences (Creswell, 2014). Member checking also assisted with identifying my own biases and misunderstandings of the data provided by participants. This additional check was crucial for this study's design because I did not review the children's documents until after the interviews. Member checking allowed me to ensure I was aligning that information with what I had learned from the parents as well as to follow up on any additional questions that emerged from the data. When any questions or misconceptions arose from review of the interviews, they were discussed with the participants. Once findings were developed, member checking was conducted via emails to ensure alignment.

Bridling

In qualitative research, it is difficult to completely remove oneself from an understanding of the phenomena of interest. Dahlberg (2006) introduced "bridling" into qualitative research as a metaphor used to represent horseback riding. The essence of this approach is that the researcher cannot simply toss aside her experiences. They were with me as I conducted my research, as I pulled the reins on the horse when I needed to control it and loosened the pull when I could simultaneously allow the horse freedom and safety. As an individual with the unique experiences to conduct the proposed study, it was imperative I had the opportunity to interject my own perspectives into the project, but also vital that I pulled back on those when they got wild or did potential harm. According to Dahlberg et al. (2008), bridling is “the restraining of one’s pre-understanding in the form of personal beliefs, theories, and other assumptions that otherwise would mislead the understanding of meaning and thus limit the research options” (pp. 129-130). Bridling calls on the researcher to understand the experiences of the participants simultaneously with their own (Ellett, 2011). As stated previously, I made it a point to identify my own biases and control my reactions and assumptions by revealing specific data to myself at specific points in the research process. I also called upon my role as an educator and parent when those were necessary to understand the stories of the participants and their experiences. Bridling allows for the pulling back of the researcher’s story when appropriate and for filling it in when it is useful.

Ethical Considerations

The ethics of this study were evaluated and confirmed by receipt of the IRB approval through UNC’s Office of Research and Sponsored Programs and through the IRB at the children’s hospital. Additionally, a data user agreement was administered between UNC and the clinic for the de-identified student information. This allowed for the access and review of the clinical and assessment documents.

Participants were fully apprised of the study information, and their personal information was safeguarded and protected to the greatest extent possible. All audio recordings, transcripts, field notes, student CVI profiles, and de-identified student documents were kept in a locked file cabinet (hard copies) and a password-protected laptop and password-protected external hard drive throughout the course of the study. Retrospective records were reviewed via the DUA between research organizations, and no identifying information of parents/caregivers or students was used in the study. Risks in this study were minimal; however, there was the emotional risk associated with the stresses and experience of being a parent or caregiver of a child with a disability (Singer & Floyd, 2006) and discussing that experience in detail with the researcher. I strived to be a compassionate listener and to honor the amount of details and story that each participant was willing to share. More information is provided in the IRB documentation on Appendix D, Participant Safeguards.

Conclusion

In Chapter III, I have outlined the sampling methods, data collection, data analysis, and ethical considerations and assurances used in the study. A small, purposeful sample was recruited from a pool of potential participants provided by the Division of Pediatric Children's Ophthalmology at the clinic. This group of participants was chosen to examine the experiences of families within the clinical and special education programs in a proximal geographical area. Convergence of the phenomena gives strength to the findings as various pieces of data are put together to promote a deeper understanding of the case (Bloomberg & Volpe, 2019).

Data collection was conducted via a DUA between the clinic and the UNC Office of Research and Sponsored Programs, through semi-structured interviews with the parents/caregivers of children who are patients at the clinic and enrolled in special education programs in their school, and clinical and educational documentation. Retrospective clinical and CVI-related assessments were shared via the DUA, and the child's most recent special education documentation was provided from the parents/caregivers. Demographic information on each participant and basic information about their child was collected via phone survey. Thematic analysis was used to develop themes and results from parents' experiences in the clinical and education environments. The content from educational and clinical documentation was conventionally coded to discern themes and categories. The following analyses and results from this triangulated data could help to understand how parents and clinicians share knowledge with one another and illuminate how that information is translated into outcomes for parental advocacy, input into educational programming, and, ultimately, student success.

Data were analyzed both within case and across cases as the data were collected and maintained. I used thematic and conventional content analysis to triangulate the data from multiple sources of clinical, educational, and personal information gathered from participants and my own reflective journal. I had a peer reviewer code data concurrently alongside me and serve as a safeguard of credibility for the study. The goal of code development was to provide a rich and thick description of the cases that addressed the research questions for the study.

CHAPTER IV

RESULTS

Introduction

In this qualitative, multiple-case study, I sought to uncover how the educational programming of students with CVI is understood by the parents through their experiences in the clinical and educational settings. I also proposed to develop a deeper understanding of how assessments conducted, at the CVI clinic and in the educational setting, paired with family knowledge of CVI are connected to the decision-making processes for developing special education programming for these children. I uncovered information about the family experiences through these processes as participants exist in both the educational and clinical constructs. This information was gleaned from in-depth, semi-structured interviews with the participants and the clinical and educational documentation shared by the participants and clinical research coordinator.

This chapter presents the three categories that emerged from the analysis of multiple sources of data collected. The categories that emerged were: (a) CVI without a TVI; (b) the shifting roles of mothers; and (c) mothers' experiences within educational systems. First, I will share narratives from the semi-structured interviews conducted with the three mothers of children who had a CVI diagnosis and who were all patients at the same children’s hospital clinic in the midwestern United States. The mothers shared their experiences of receiving a diagnosis at the clinic and the journey that followed for them and their child. To understand the participants’ experiences at the clinic, in special education meetings, and how the needs of their child's visual disability are met in the educational setting, the following research questions were developed.

Q1 What are a mother's experiences of their child's special education programming and goals for meeting their CVI-specific needs?

Q2 How does the mothers' understanding and knowledge of CVI contribute to the educational programming or services provided?

Q3 How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?

First, I will tell the stories of each mother and her child. These narratives are initially presented as singular stories, then woven together because they are linked through their experiences of raising a child with CVI. The participants answered the open-ended interview questions in honest and meaningful ways.

I am entitling this section "Herstories" because the participants are all mothers of daughters, all identifying as females. The mothers relayed the stories of their child's journey since their diagnosis of CVI and the ways it has impacted their lives. The narratives of each mother and daughter are then analyzed within cases and across cases to provide the above-mentioned categories that emerged from the data.

The participants in this study all received services from the same children's hospital clinic that specializes in CVI. Staff members administer evaluations, which integrates information from a multi-disciplinary educational and clinical team and the child's parents. They provide a variety of services as well such as physical therapist (PT), occupational therapist (OT), and speech language pathologist (SLP) and supports from TVIs who are on staff. Thus, the clinic staff referred to in these interviews have had extensive training in CVI from their pediatric ophthalmologists and work in the field of identifying, monitoring, and treating visual impairment in children.

In the second part of this chapter, the special education and clinical information gathered from documents provided by both the clinic (via the DUA) and the parents (via the parents through the DUA) are presented using visual organizers so the reader can reference and digest the information to access the analysis and results section towards the end of the chapter. The final analysis is the result of triangulating the data from the interviews and documentation. At the end of the chapter is the discussion of the findings of the categories as they lead to themes from the data collected and triangulated

Herstories

Case I: Jenny

Jenny's mom is uncertain about her birth history. "The information we have is that the day she was born, she was taken, or she was found, and she was brought to an orphanage, we're not sure that's true." Jenny's parents were told she was most likely born premature and was in an orphanage in China for the first three years of her life.

During her time at the orphanage, Jenny had very little interaction with the world. She did not build relationships with caretakers in a typical way. Jenny was bottle fed until she was 3 years old and still has eating issues as a result. Sometime during her stay at the orphanage, Jenny was able to attend a preschool run by Australian missionaries. She was introduced to developmentally appropriate toys and to other children, but she went back to the orphanage at the end of each day. While at the orphanage, Jenny spent weekends and nights in her bed.

Two years ago, Georgia and her husband, Brad, adopted Jenny from China. She arrived to them with disabilities they knew little about and spoke little bits of a language they did not know. The parents of two typically developing children of their own were not sure what they were getting into.

Diagnosis

As Georgia and Brad got to know their daughter, they also learned about her disabilities and the challenges she might face. Because Jenny was not introduced to solid foods at the developmentally appropriate period, she had eating issues that continue to be a challenge. Her communication is delayed as well. At the children's hospital in their area, Jenny had a cat scan that showed that a portion of Jenny's brain (in the back) is dark. Georgia elaborated, "The doctor estimated she might have lost 9-10% of her brain volume and that the damage extended to all four lobes." The doctors also told them that Jenny most likely had a stroke in utero.

Jenny wears glasses for astigmatism, but other than that, her eyes are fine. Her parents, though, had noticed that she had difficulty with tasks and activities that they felt she should be able to do. "You know, we got her, and she had been institutionalized for years, and we were trying to figure out, is it her vision or is it just that she's never been exposed to a puzzle?" As a patient at the children's hospital, she also saw a pediatric ophthalmologist there. Through this relationship, Georgia had shared that Jenny got very close to things she was looking at (even though she had normal visual acuity) and had difficulty with spatial concepts. Jenny also had a hard time doing puzzles. There were some quirks that Georgia did not see in her biological children who were all typically developed.

Staff at the eye doctor's clinic asked Georgia some questions from a questionnaire. These questions were related to the way she functions within her visual environment: "Does Jenny have difficulties seeing things at a distance?" "What about the way Jenny looks at faces?" "What about the way she pays attention to certain things, or isn't able to?" The staff asked about things that Jenny's parents had seen, but just were not quite sure what they were seeing. Jenny's OT had also noted that she had challenges with specific activities and difficulties paying attention, especially when tasks were hard or there was a lot of visual information. Jenny received a diagnosis of CVI from the clinic. The hospital staff knew that, based on her birth history, Jenny was at risk for CVI. Her parents' information from her home and school life confirmed that she did have issues processing visual information.

Now, in 2021, Jenny is a kindergarten student at a Montessori school. She is not currently being served by a TVI. She is beginning to write letters, draw pictures of people and her family, and cutting and pasting with her classmates during activities. According to Georgia, she has a very big personality for a 5-year-old. During our interview, Jenny came into the camera frame numerous times, wearing a giant pink bow, a frilly dress, and a pair of dangly earrings. She looked into the camera and asked who I was. She wanted her parents' attention.

Jenny's family lives in the southeastern United States, and Jenny started kindergarten at a Montessori for the current school year of 2021 through 2022. She attended public preschool. She had outside therapy services from the children's hospital clinic, and her team felt the hands-on experiences were benefitting her. Jenny's family wanted her to repeat her last year of preschool, but the state said she could not.

Mother as "Teacher of the Visually Impaired"

Jenny's teacher is willing to accommodate her CVI, but only because Georgia is willing to give her information about it. Because she attends a private Montessori school, school-based vision support is not an option.

> I gave her all the stuff on CVI, like all the information from the doctor, and all of her OT notes, and there were some suggestions in there of how we can help her at home. I told her I realize you're a private school, I'm not asking for you to be like a public school, but she's willing to try things, to make things work.

Georgia shared that she uses the information the clinical staff gives her about supports and strategies for learning during Jenny's therapy sessions. She also stated she appreciated the information from the ophthalmologist that works with Jenny. When asked how Georgia gives information to Jenny's teacher, she responded

> Can I start with how I talked to her teacher, like I said, I just wanted to let you know that [Jenny] has cortical visual impairment and you know, I wanted to take the burden off of her because this is a private school. They truly do an amazing job. The love and care she gets there; I feel outweighs like some of the other things. . . . I said "Hey, would you be open to me giving you some tools, telling, and teaching you a little bit about CVI and giving you some information that would maybe help you and make sure it's engaging for [Jenny]?"

Just as a teacher of students of visual impairments would offer tools and materials and bring in products to accommodate the needs of a student in the classroom setting, Georgia provided a lightbox for the classroom. Jenny had success during her therapy sessions writing on an illuminated surface. Georgia brought that information into the classroom setting and showed the teacher how to use it with Jenny.

Georgia was also familiar with educational assessments that the teacher was doing with Jenny,

> They did an assessment with Jenny at the beginning of the year, and it's a normal assessment that I've seen, you know, because my boys did it. So, it's like a lot of letters and which ones can she identify and numbers and shapes and rows of things to count. And, you know, I just pointed out to her like some of the things may be visually too much for her to see. So, I gave her an example of a page that had 15 things to count, and I said

> one way she might be able to count all of these is if you have a piece of blank construction paper and you put it on the page and cover up everything else visually.

Georgia feels that with the support and the plan they have in place, Jenny has made progress. She can see (for example) that Jenny now draws recognizable people and is putting letters in the correct order.

Cerebral Visual Impairment Knowledge

Georgia has learned about CVI from a few different sources. She mentioned blogs, YouTube, and Facebook groups as internet resources. She also mentioned Patricia, the OT at the clinic who provides monthly services to Jenny.

> Patricia has taught me a lot, and there’s a guy on the internet that I’ve watched a lot of his videos. It’s an older gentleman. I think he might have had like a brain injury. I’m in these groups on Facebook with other parents, and he’s done all these videos, and they’re on YouTube. But he talks about his experience, and like how he sees things, and it’s really just helpful. Patricia even asked me to send them to her.

Georgia relayed that she understands that her child does not necessarily see in the same way this gentleman sees, but it is helpful for her to even attempt to figure out what Jenny does see and what she might experience later in life or as a teenager.

As helpful as the information from the internet is, Georgia communicated that she has tried to find other moms that have adopted children who also have CVI or visual impairment. She is hoping to meet to meet someone to share knowledge with regarding CVI. She has a neighbor with a child with CVI who has severe disabilities, and she said she thinks their experience is very different and that vision is not a priority for them,

> I do just wish like just more people knew about CVI. Especially just like even within the therapy community. Like they've heard of it, but they just don't have a lot of information. I know different therapists specialize in different things. I just wish there was like more resources.

School Experiences

Jenny has an IEP that is kept up-to-date even though she attends a private school (see the next section in this chapter for a summary of her services and more detailed information). Information gathered at the clinic (from evaluations, doctor visits, and therapy sessions) are integrated into her educational plan.

> I think they use it some. But I think and I'm not, I'm just not sure. I was worried about still like how were things going to go even if she was in the classroom [public school] like because she's not going to have a TVI with her all the time. So, the classroom teacher is really important, and has to be open to helping and understanding.

Her mother is obviously proud of the progress she has made and when she is able to see pictures from Jenny's classroom, she sees a little girl who is cutting and pasting and giggling with her friends. Georgia sees a little girl engaged in age-appropriate social interaction.

> Jenny can't wait to go to school every day. She is excited to be there, she loves to be there and loves the other children. Jenny fits right it. She does take a little more instruction and guidance, but she's been able to do the work. I feel like it's amazing, it makes you feel so good.

Georgia was worried about the social implications of Jenny's disability and history. She conveyed that she became aware of the social skills you learn in the first few years of life that Jenny was not exposed to, and that Jenny has, amazingly, become much more social than her biological children were at the same age. “She has done really well. She has a yoga class. She loves art, she loves music. She loves to dance and sing and do all of that, she is as wonderful as all of that.”

Am I Going to be Able to Help Her?

For all the of the progress Jenny has achieved, Georgia is realistic about the road ahead, “I do get a little bit overwhelmed like is she going to learn to read? Am I going to be able to help her? Am I going to be able to help her learn letters and then, I start thinking about multiplication tables.”

At this point, you can see Georgia is overwhelmed just thinking about this. She mentions she has a friend whose high school aged son has autism. “She has a lot of experience with IEPs, and so I’ve gotten to know her, and she’s like, I will help you get through your IEP meetings. Like I do feel it’s going to be a battle.” But presently, Georgia reflects on Jenny’s growth and where she is now. “I mean she’s just come so far, like it’s amazing, that’s the most exciting thing just to see. I mean if you knew her from day one, it was like, how are we going to do this with you?” They’ve done it, and they will keep doing it because it is what their child needs.

Case II: Abby

Abby’s mother, Bridget, does not know the origin of her disability. Abby has cerebral palsy and CVI. The doctor was never able to pinpoint why Abby was born with these conditions. She was not premature, but her mother was on bedrest during her pregnancy and was diagnosed with low amniotic fluid. Abby’s medical history includes apraxia, failure to thrive, hypertension, left ventricular hypertrophy, and unspecified developmental delay. Past brain imaging showed areas of her brain that were never developed. Abby is also a patient at the children’s hospital clinic where Jenny (from our story above) goes for doctors' appointments and services. Abby is 7 years old and attends second grade in a public elementary school.

Diagnosis

Abby received her CVI diagnosis in 2019, at the age of 6. The OT at the clinic evaluated Abby. She also went out to Abby's school and gave in-depth information about what the diagnosis was and what it meant for Abby. "They went over CVI, a lot of what CVI is, and what they can do for kids with CVI." Bridget learned about CVI through her experience at the clinic. Bridget shared that hearing the information again also made her think about CVI in another context as well:

> So that was really helpful for me. I had already heard it all because I had gone through all of the reporting with her. But then, you know, it was really good for Abby, for her [the OT] to come to school and give an overview. I honestly think after I learned more about it and what it is like I feel like it's . . . I feel like a lot of kids get diagnosed with ADHD [attention deficit hyperactivity disorder] actually might have CVI instead of ADHD because it is not well known and the symptoms and the results of it are so similar.

Here, Bridget hits on a common concern among CVI researchers; that the behavioral manifestations of CVI can be misinterpreted as other cognitive or behavior disorders (Chokron et al., 2021). Bridget was comforted to know that Abby did not also have an ADHD diagnosis, "It was good to know, that it could be the result of her focus issues, or you know a result of something else, and really made a lot of sense when she [the OT at the clinic] went through everything." Bridget continued, "If we had not gone to the ophthalmologist that we did at children's, we would never have known because they're the ones that came in that said, well, maybe we should be evaluated for CVI." After the interview, in a follow-up email, I asked Bridget a bit more about what she felt were the differences between ADHD and CVI.

> There are a lot of similarities, but the differences are harder to see. I think what I've seen with ADHD, my oldest daughter is more fidgety and in motion. While I see some of that in Abby, it's not the same. She becomes uncomfortable when she's being challenged and needing to focus. But, where Abby can focus when reminded, a kid with ADHD has to try extra hard. The fidgetiness comes naturally with ADHD, where I feel like it depends on the environment with CVI. Also, I don't think ADHD comes with the same level of visual anxiety that I see in Abby. My oldest doesn't get overwhelmed by space, special relationships, or visual overstimulation. She'll get distracted for sure, but Abby gets anxious and nervous. She has a hard time processing all the visual variations.

Doctors have prescribed medications for Abby that are used for ADHD to help her with her focus and attention. For now, Bridget doesn't want to go down that road until she has to. She admits that the medications might help with her anxiety, but she also knows that the anxiety can come from a place of her being overwhelmed in certain environments because of Abby's CVI. Bridget wants to ensure she is not causing any more problems for Abby and that her CVI is being addressed.

Learning Experiences

Abby receives OT, PT, SLP, and vision services in her school. She is in a general education setting for about half of the school day for group activities and morning routines. Abby is in a special education setting in small-group activities for the other half. Bridget is involved in her educational planning and has a comprehensive grasp of Abby's academic and social challenges. Her involvement with Abby’s education was born from lessons she’s learned from having an older daughter who has ADHD.

> I’m pretty involved. I understand the IEP process. I know what her needs are and what her goals are. The school does a fantastic job of, you know, keeping track of all that and keeping me updated on her progress and knowing what her needs are beyond the IEP, just kind of knowing her. My other daughter didn’t have that support, so I had to switch her to a different school for kids with disabilities and ADHD.

I asked Bridget if a vision professional other than outreach from the clinic has come in to give Abby’s special and general education team information about CVI.

> I’m haven’t heard anything other than that initial visit which, you know, I’m not sure how much it was well received or not. You know, it just seems like another thing that they have to keep track of, and they have a lot on their plate already. The lady that comes in quarterly, I don’t know what her interaction is with Abby or the other students or the staff. It’s probably something I could ask.

The lady that Bridget is referring to is the TVI. On Abby’s IEP, her vision services are listed as 30 minutes monthly and listed as a related service. Related services on a child’s IEP refer to supportive services that a child with a disability requires in order to benefit from special education (IDEA, 200, AB 300.34). The classroom teacher writes a note in Abby’s home communication log that the vision teacher had come, but Bridget did not have any other information about what she did during their sessions.

Bridget knows that they use materials in the classrooms to help Abby with her CVI. She relayed they sometimes use a slant board,

> I think it’s a matter of maybe preference for her, or if she’s struggling with something, they’ll bring it out and say, you know, let’s put this on, and they also use highlighters for things. When there’s a lot of information on things, they’ll, you know, black out stuff. There is so much clutter in those classrooms, and it’s overwhelming for adults.

Abby spends the other half of her time during the school day in small-group instruction, in a room that her mom assumes is quieter and more secluded. I asked Bridget if she knew if any of Abby’s IEP goals were specific to her CVI, and she said, “I don’t think so, no. I don’t know how they would because they don’t have someone who can work with her all the time, right?” Abby has OT, PT, and SLP goals, and she sees those practitioners at school more regularly, all at 90 minutes per month. Abby has challenges with literacy and math. As mentioned above, she is in the general education classroom for some group activities and morning routines. She is in a small group, in a special education setting, for her academics and to work on goals. Bridget feels as though Abby’s school team addresses her CVI to the best of their ability,

> I guess as much as possible they’re able to. So, you know 100%, probably not. But I think they’re doing what they can with what they understand. And I think, I mean, she’s got a lot of other educational needs to address, so yeah.

Towards the end of our conversation, Bridget mentioned that she should check in with the TVI and team to see the supports in place and to see if they could share any successful strategies at home.

Abby is very social. According to Bridget, she has a shining personality which is also evidenced in her team reports and inputs on her IEP documentation.

> She’s happy all the time. You know she hugs people and just loves on people, and it kind of makes you feel like you’re the most important person in the room. So, I think that’s

> where she really succeeds. Educators want to help her because she is very easy going and easy to love and work with.

Keeping up with her peers academically is her biggest challenge according to Bridget, “She just is way behind. Even, you know, basic concepts for math and writing, and it’s just a struggle.” Abby struggles to attend and pay attention. Mom noted this as her biggest challenge when working with Abby personally--on homework, for example.

And while Abby’s personality and social relationships are some of the more positive parts of her formal educational and special education experience, Bridget worries that as Abby gets older, it will become more challenging to start and maintain those relationships.

> I think the divide, the gap, is going to be more apparent and she, you know, is just not comprehending that. She doesn’t have those social cues of kids not wanting to play or that she’s different and she just wants to be everybody’s friend and play, and I mean, every time we go anywhere or go to the playground, she finds a friend.

Finding friends is a big part of a child’s educational journey and again, listening to Bridget’s uncertainties about the future, I was reminded that I feel the same way for my own child. You want them to have a full life, you want them to succeed.

Case III: Grace

Paula has the most unique participant profile in my study, most unique because she has been an educator for more than 30 years and currently serves as the principal of the school Grace attends. Paula is a principal of a Christian school in the southeastern United States. Her daughter, Grace, is adopted. She’s been with Paula and her family since she was 5 1/2 months old. She was born premature, and Grace’s biological mother overdosed on diabetes medication before she was born. She was kept on life support so Grace could be delivered. Grace weighed 1 pound 14 ounces at birth. She was abused by her father and was diagnosed with ROP as well. Besides CVI, Grace's diagnoses include prematurity, CP, ADHD, and mild hearing loss. Grace also suffered non-accidental trauma (NAT) as an infant. She was dropped as an infant, and her ribs were broken. Grace is now 8 years old.

Grace was adopted from a distant cousin of Paula's. Her mother overdosed and was kept on life support so Grace could be delivered. Paula got a call from a distant cousin who asked her to consider adopting Grace. At the time, she had a discussion with her husband, and they decided they had to do it. They were told if they didn't, she would be "put into the system." They knew it would be a challenge,

> We had good friends that had a preemie. They had, you know, because of lack of oxygen and all the things they give; we knew she wore really thick glasses and always had things wrong with her eyes. So, when she [Grace] came to us, I knew these issues could be a possibility.

She did not consider CVI at the time but knew there would be vision problems. Grace had laser surgery to treat her ROP as an infant.

> I had to take her to the ophthalmologist over there and, my gosh, she was just so tiny. I knew when we got her at 5 1/2 months old and I had to take her to an eye appointment and I'm like, oh my goodness, how in the world, and then, when I watched the first time, they clipped her little eyelids back.

This was just the first of many doctors' appointments Grace's family will take her to and support her through.

Diagnosis

Grace is a patient at the same children's hospital as Abby and Jenny. She also receives therapy services at the clinic. Grace was diagnosed with CVI when she was 5. Grace was also a patient in the CP clinic at the children's hospital, and Paula had accepted that she would have to bring Grace to the eye doctor annually. "The doctor at one of the appointments was like, she has cerebral palsy, have you ever heard of CVI, and would you mind her being tested for it?" At that time, Paula had never heard of CVI, and she relayed that she did not know what to make of it at the time and still struggles today.

> To be quite honest, I still don't think it's voodoo, but at the time, I was like this sounds like something like voodoo. I don't even know, like, I can't put my hands on this. I don't understand, like, we're not getting a prescription for glasses, but we're being told that she has, you know, that she possibly has this and then when she did get the diagnosis . . . I mean the doctors were amazing, but when the woman started testing her, it just made so much sense. Yet, I still don't understand it. I will say I struggle. I have struggled the last two years to try to explain it.

She communicated that she recognized Grace's behaviors, but couldn't pinpoint the origin, "It makes sense, there were so many things like, okay, so now I do believe the diagnosis because you're telling me things that are confirmed, that I've seen before I ever got this diagnosis." Paula thought the behaviors were part of her other disabilities. She said Grace was fearful when walking, she always held onto her family, and she would fall a lot. Paula now had this information from the clinic staff and doctors. She now needed to understand what it all meant in relation to her daughter's experiences. Though Grace attends a private school, the county she lives in provided support once for her CVI, and a TVI was sent from the state school for the blind to do an evaluation and attend her IEP. Paula also keeps Grace's IEP current. "She [the TVI] was amazing, and she sent us a video, and I've used that the last two years, and when the teachers look at it, they're just like just, wow, that's what she sees or that's not what she sees." The video Paula refers to is from the perspective of an adult with CVI who explains what it's like to enter a crowded restaurant when you have CVI and how overwhelming it all is.

> After the appointment when she got her diagnosis, she came down the hall to get her medicine, in first grade, they were sending her down the hall and then I watched that video, and I was just like . . . and, she was scared, like, by the time she got all the way down there, she was almost shaking, and, you know, and then I sent it to the teacher and she's like, oh gosh, it's almost like we've been abusing this child, because you've made her walk down a hall!

Paula now had a greater sense of understanding, but she communicated that she is still overwhelmed by how to deal with Grace's CVI diagnosis and to do the best she can do for her.

Learning Experiences

Grace's school situation is a bit unique and, admittedly, Paula recognizes that Grace would probably not be receiving the supports she does if her mom was not in charge of the school. Grace currently has therapies at the children's hospital clinic, but her school has someone with a background in special education who works as an interventionist. Grace also has access to a speech therapist through their county and a counselor who she sees outside of school. Grace does not have a TVI, but the TVI from the state school for the blind told Paula she could call her anytime. Paula refers to her as a "liaison."

Just as with Abby, the clinic staff at the children's hospital came to teach Grace's team about her CVI diagnosis after she was first diagnosed. Currently, Paula is really the architect of Grace's special education programming and is in charge of the supports and modifications for her daughter's work. She also buys materials and products that Grace needs in the classroom to help with her CVI.

Grace currently gets pulled out of the regular classroom to focus on academic instruction in areas where she needs it. Grace was recently reevaluated by the neuropsychologist at the children's hospital, and her IQ score dropped, so Paula and the intervention specialist agreed to work one-on-one instruction into her plan. She has trouble paying attention and focusing, especially in busy environments.

Mother as "Teacher of the Visually Impaired"

The school that Grace attends is kindergarten through 12th grade. They are one of the only private schools around the area where they live that has an interventionist and some services for children with special needs. I asked why Paula chose to send Grace to her school, aside from the obvious reasons of her presence. The reasons are personal. She and her husband and their three biological children are graduates from the school. She notes the class sizes are smaller, and the community is close knit.

Grace received early intervention services and went to public school for preschool. Paula admits that the ratios at her private school are much smaller. They have 15 children at the most in a classroom. She also receives the other services mentioned above outside of school:

> Even though she may not have gotten the services at school that she qualified for, we still were able to get what she needed here, and we're still at the point that if something else is going to meet her needs better, we'll do it.

Currently, Paula is the one who meets Grace’s needs as related to her CVI. She received a lot of information from the clinic staff, her vision liaison, and online resources. She relayed,

> So, when the gal [TVI] came in, it was two years ago. Not only does she work at the school [school for the blind], but she also knows a lot about CVI, and she sat across from me, and she literally maybe said more than she should. I don’t know, I could just tell, but she said, like, there’s, like, nobody in the county right now to serve her. They have one person, and our liaison tells me that she doesn’t really know. . . . I know there’s differences and trainings with you all. Like, I think she’s a special ed teacher with a little bit of, like, vision background.

I asked how Paula shares the CVI knowledge with Grace’s teachers.

> I sit down with her teachers, you know, and tell them everything. The adaptations and the interventions are being pulled from the __________ hospital reports and the school for the blind evaluation. But there’s no, how to say this, there’s, I think my biggest thing that kind of drives me crazy as an educator and a parent is I’m interpreting it and I don’t, I don’t have a special person here every year to say, this is what this means. I did when she was first diagnosed, you know, the lady from [the clinic] came, and we did the training in Grace’s classroom. And so, you know she could see where Grace sees and tell us. That doesn’t happen all the time, that was the only time and so, it’s my interpretation of somebody who is not a doctor, somebody who is a lay person and doesn’t understand CVI.

Paula is the lead school administrator and the child’s parent, and she also plays the role of the TVI for her child. She admits when asked if she feels Grace’s needs are being met that she would give herself and her school a 6 out of 10. “I don’t know,” she finished. Paula is doing the best with the information and resources she has. She also adapts Grace’s work visually and buys equipment she needs. Paula uses word bubbles to help Grace learn to read. Word bubbles are intended to teach children with CVI how to read. The word is presented in a high-contrast bubble letters with all the letters presented next to each other creating one shape. It is not an evidence-based practice, but is shared in TVI, parent, and CVI groups. Paula also provides slant boards and adapts her books and math assignments. She is really doing all she can, but she frequently does not feel like it’s enough.

Learning Experiences

We discussed Grace’s biggest successes and biggest challenges. Her mother recounted her numerous injuries and medical issues as an infant and how she has overcome a lot of them. Grace is resilient. Grace is a fighter. She has managed to walk and talk, even though the doctors told Paula she would not. She has strong social relationships with her peers and her family. Paula recounted a story that should be shared. She told a story about Grace’s peers and their understanding of Grace.

> In a smaller school--and our kids aren’t perfect by any means--but when they grow up together, they learn what they can and can’t do, and like today, I’ll give you an example. I’m walking down the hall, and I’m like, the teacher didn’t think about this, and she put her [Grace] at the back of the line, and they’re walking down the hallway. And I’m, like, “Take off your principal hat, take off your teacher hat and just watch.” I was, like, I’m just going to walk back here with her, so she doesn’t feel alone. Well, a little girl that she’s been with since preschool, all at once, just, nothing was ever said, just stepped down the line and went behind Grace. And this little girl _____ she knows that this helps Grace, and she just did it, no one asked her.

Academically, Grace struggles with math, literacy, focusing, and paying attention. When I asked what brings her joy about Grace, Paula had to talk her way through it. Not that she could not find it, but she had to dig deep. She had to remember how hard Grace has fought.

> Sometimes I have to stop and think of the joy and write it into my journal. But it's like what could be and what is. Sometimes I have to go back to what could, you know, if we weren't helping or if she wasn't receiving this, and she's a joy to others so. She really does bring joy to others.

Am I Going to be Able to Help Her?

Grace has behavior problems at home. She is on medication for ADHD, and Paula shared that they do seem to help her with the extreme emotions she experiences. Paula's own biggest personal challenge is,

> I think it's the, it's the unknown. I mean, I've been in education for 30 years; this is my 32nd year. It sounds like, wow, you're pretty crazy, you don't understand, but I've never raised a child with special needs and so I don't . . . I can't help you; you give me your paperwork. You give me your diagnosis, and we can do all the professional types of things, but when I go home and I'm living with it and I'm, you know. It's like any educator, you put your head on your pillow and did you do everything you could for every child. I have a child with special needs and you're also trying to do your best, and I don't know how to help her sometimes because I don't know, I don't know what I don't know, and I don't know how to make her know.

Paula wishes that she understood CVI better and that professionals in the system understood it better and could help. She needs to be able to help her staff with it, and herself, and

Grace. Repeatedly, she voiced the need for resources and support and wondered if she is doing what she can with the information she has.

Case Analysis

In the stories above I have presented the rich narratives gathered from my interviews with three mothers of children with CVI. Each has her own unique perspectives and experiences. To analyze the data of a study is to scrutinize the components of the data, specifically focusing on discourse and the power behind that discourse (Bloomberg & Volpe, 2019). What is powerful about these firsthand accounts from the mothers of children with CVI is revealed through the subthemes gathered from the categories: (a) CVI without a TVI; (b) the shifting roles of mothers; and (c) mothers' experiences within educational systems. These were gathered initially within cases and then across cases through the methods of thematic analysis (Braun & Clarke, 2006) which uses analysis to generate codes and derive themes from codes as they emerged from the interview data. Participants provided information in the interviews gathered from the physical spaces (home, school, clinic) emotional places (overwhelmed, anxious, proud), and social interactions (relationships with child, school, clinic, community) of their lived experiences having a child with CVI.

The proceeding analysis focuses on the categories gleaned from the data and the related themes that emerged from those categories through the data analysis. For the purposes of this study, the data gathered from the interviews served to answer two of the three research questions originally proposed for this study.

Q1 What are the mothers’ experiences of their child’s special education programming and goals for meeting their CVI-specific needs?

Q2 How does the mother’s understanding and knowledge of CVI contribute to the educational programming or services provided?

Categories and Themes Revealed

Mothers’ Experience of Shifting Roles

A major category that emerged from the participant interviews was the shifting roles and responsibilities of the mother. From this category, the theme “mother, advocate, professional” emerged. Mothers’ roles shifted from caretaker to advocate, to CVI and visual impairment resource, to teacher, to educational team lead. As each participant's interview progressed, the experiences of living within each of the different roles (and sometimes multiple roles at once) emerged as sources of responsibility, anxiety, and opportunity as the mothers explained the myriad of ways in which they support their daughters across different environments.

Mothers who participated in this study took it upon themselves to provide information about their child’s CVI to their child’s educational team. For Jenny and Grace, because they were placed in a private school, they did not have a TVI or vision professional who saw them on a regular basis. Their mothers kept their IEPs current so that they could work on goals and receive services if they were available or ever reenrolled in public education, but they did not have the support provided by someone with expertise in visual impairment within their classroom settings. Jenny’s mother, Georgia, understood that she needed to provide the teacher with the information she had learned during Jenny’s CVI evaluations and therapy appointments.

> Can I tell you how I talk to her teachers? I gave her all the stuff on CVI, like all the information from the doctor, and all of her OT notes, and there were some suggestions in there of how we can help her at home. I told her I realize you’re a private school, I’m not asking for you to be like a public school, but she’s willing to try things, to make things work.

Not only does Jenny’s mother provide the information, but she is also understanding of the situation. She went on to describe visual accommodations and modifications for classwork and assessment as well as ways to engage Jenny. In this instance, Georgia is her mother, her advocate, and her TVI.

Abby’s mother informed me that she was very involved in her daughter’s IEP process. Bridget knows her needs and her goals and that she felt the school did a good job at keeping her up to date on the information regarding her progress and challenges. Abby’s mother acted as an advocate in the past for her older daughter who had a diagnosis of ADHD when she was in the public-school setting: “The school she was originally at didn’t have that support.” When Abby received the CVI diagnosis, Bridget went to her special educators and requested a reevaluation to determine how her team could meet her needs, now that CVI was a factor. Again, Bridget acted as an advocate. Bridget’s previous experience as an advocate for her older daughter provided her with the background knowledge to understand how to support Abby’s team.

All the participants in this study take on the role of teacher when their children come home from school, and they have homework to do, or they are trying to engage them in academic work. Jenny’s mother showed me the “bubble letters” Jenny’s old TVI made for her that she keeps on the fridge and regularly works with her on. Bridget and Paula attempt to do homework with their daughters, just like other mothers, but they must focus on their CVI-specific needs. These involved providing them with breaks, modifying their work, and adapting their assignments into manageable chunks, which they stated was challenging even if it was for a very short amount of time. Paula stated, “I wish she’d do for me what she does for her teachers, find a little bit of that at home for me for like 15 minutes of homework.”

This was very tongue-in-cheek, and a parent does not have the same strategies and supports of the classroom teacher nor the expertise of a TVI who is knowledgeable about CVI. She professed the challenges of the changing roles, “We can do all the professional types of things, but when I go home and I’m living with it.” The frustration in this statement was palpable. The constant shift of principal to educator to CVI resource to the team and then the transition into their homelife feels overwhelming.

This experience of shifting roles is also evidenced by participants across their comparisons about being a mother to typical children versus being the parent of a child with a disability. Paula expressed this when asked about her challenges, “The educator in me wants to believe that she’s going to be like my other three children, and she’s not.”

Paula, due to her professional role as the principal of Grace’s school, has no choice but to role shift on a constant basis. She plays advocate, educator, parent, boss, and principal as she navigates Grace’s educational needs and challenges. She relayed she gets whatever resources that Grace needs and is really the architect of her support plan. When she told me how she highlighted every word in Grace’s bible verse workbooks, she was playing the role of TVI. When Bridget was told her daughter should go on an ADHD medication even though she does not have ADHD, she advocated for the choice to say no, “I don’t want her to go down that road yet.” She felt now that she knows about her CVI and there is a plan in place, then interventions might be able to help.

Mothers’ Experiences within the Educational System

Another category that emerged from the data was the mother’s experience within the educational systems which revealed the sub-themes of navigating educational landscapes and apprehension and possibility. The sub-theme of apprehension and possibility emerged because of the mothers' hesitations about the adequacy of their knowledge of CVI and its ability to help their daughters and the possibility of how their daughters have overcome challenges and their social successes. Possibility also emerged as a sub-theme through hope for future research and knowledge to shed more light on CVI and how to help their children. This was also communicated by their participation in this study.

Participants selected the settings in which their daughters receive educational services. Each one had a slightly different reason for their decision. Having a child with a disability means there is a much different terrain to navigate than just report cards and teacher conferences. Special education comes with meetings, evaluations, and a deficit-based system that reveals a child's shortcomings at every turn. Providing information to teachers about their child's vision and other needs, understanding academic and social challenges, providing resources, promoting self-advocacy, and the lack of options some of the participants felt regarding a setting in which their daughter could be successful all emerged from these themes.

Abby felt the public school supported her daughter with CVI, but not her daughter with ADHD and additional disability. Paula, her husband, and her three biological children attended the school where she is principal, and she felt that Grace would not receive adequate services in a public school setting anyway. Georgia wanted Jenny to stay in the private school where she had a sense of community and small class size. Georgia and Paula relayed that they feared vision services would not be provided in the school. Georgia had an experience with the TVI in preschool who did not think Jenny had anything wrong with her vision; Paula heard from her state school liaison that the entire county only had two TVIs, so they selected learning environments they felt comfortable with and prioritized community and took it upon themselves to provide the vision support or link their child's staff to vision resources. Georgia sated that the

"TVI wouldn't be in the classroom all the time anyway." When we discussed keeping Jenny in the private school, Georgia stated she felt that Jenny's needs were met in terms of CVI, and she shared that she chose the school because it was a supportive environment that cared for her child.

The mothers shared that clinic staff provided presentation and information on CVI after their daughters received the diagnosis. It is unknown if this is usual practice, and Bridget was not sure how helpful it was to Abby's team because it was "just another thing for them to keep track of."

Participants' explanations of their child's academic challenges at school were aligned with the challenges relayed by the parents and confirmed during assessment at the clinics as well. All participants said literacy and math were a major concern. Paula and Abby both said that their daughters could not keep up with their peers academically, and it was a struggle. As a kindergartener, Jenny is just beginning to put letters in the right order and create recognizable drawings. She struggles with counting and beginning addition and subtraction.

The social demands of school also came into play during the interviews. While Georgia was excited by her kindergartener's social skills and outgoing personality, both Paula and Bridget felt that while their girls were loving and sweet, they worried about how peer reactions might change as their daughters progress through the grades,

> You know she wants to be friends with everybody. I think, you know, getting into second grade, and unfortunately, and older grades, I think the gap is going to be more apparent and she, you know, is just not comprehending that.

Paula worried about Grace's recent weight gain and seemed to make a connection between the children at her school being more understanding of disability than the children in the public school. There is some bias involved here as she is the principal, but Grace has been with the same students since kindergarten and Paula relayed that they understand her needs. Both Paula and Bridget said that their children have learned how to advocate for themselves in their own ways, whether it be asking for vision supports in the classroom when they need it or a subtle conversational shift that tells their teachers or therapists they are done with an activity or lesson, or that it is too hard.

Apprehension and Possibility

There is a sense for these mothers of children with disabilities that they are overwhelmed by what the future holds for their children. With support, knowledge, and new research on CVI, there is a hope that more resources will be developed to help their daughters. There are also apprehensions surrounding their social relationships, the complexity of their disability, a lack of information, and a lack of community or a place to go and talk with other mothers or people about the CVI diagnosis and what it means for their child. This theme is about frustration, and it is about being overwhelmed, but it is also about hope.

Paula struggled greatly with it and stated she thought it a sort of “voodoo” when she first discussed it with the eye doctors and therapists at the clinic. The word voodoo, of course, is both fear- and panic-inducing as it has devolved from an actual religion to being a cartoonish premise misrepresented as a scary unknown. But by choosing a term like this, it is clear to see how little this diagnosis can make sense to someone hearing it for the first time and how difficult it must be to accept that diagnosis for your own child.

The flip side of the voodoo remark for all participants (including Paula, once she was able to connect what the clinic staff was saying to her own experiences) was the relief of having your suspicions about your child’s behavior confirmed and having a name to assign to it. All the participants stated they knew something was amiss in their child.

“Even before we had a diagnosis, we could just tell, you know, well obviously, she sees, but there were just a few things that were a little bit off,” was Georgia’s response to the question, “What do you know about your child’s vision?” Paula’s answer was that what she knew about Grace’s vision was what she has been diagnosed with. Grace had a complicated history, and her parents knew that she would have vison problems due to her prematurity. Paula told about those moments when the doctor explained CVI to her, and then they started the evaluation, stating that “It just made so much sense, but I still don’t understand it.”

This is a paradoxical statement. Even experts in cognitive and vision sciences do not have a complete grasp of CVI. It is not surprising that an individual with no background in either of these areas would not be able to understand comprehensively, and these experiences further solidified the dire need for qualified personnel who can provide adequate services to children with CVI. The label helped confirm Paula’s experience as a mother who had questions about her daughter’s behaviors.

Bridget expressed relief that her daughter did not have ADHD--which was a diagnosis she had already dealt with. For her, it also confirmed challenges she had noted, but not fully understood, and answered questions she had. From the point of diagnosis, the challenge was then to help other people in the child’s world understand the disability to help her succeed.

But the pathways to success are difficult to discern if you do not have the information. All three mothers expressed frustration with the lack of resources for children with CVI. Paula and Georgia noted the lack of access to personnel with experience in CVI and the lack of resources for their child’s visual impairment in the public-school setting. Bridget, while finding her child’s vision services adequate, still relayed that it was difficult to find information and that she would not have information about it at all if it were not for the clinic evaluations and expertise.

All the mothers expressed understanding of their child’s academic and social challenges, but they also expressed the joyful experience of how much their daughters have overcome. Starting out as infants with problems, they used terms such as “resilient,” “fighter,” and “overcome” to communicate their pride and surprise at their ability to overcome some facets of their disability.

Cerebral Visual Impairment without a Teacher of the Visually Impaired

The sub-themes of team CVI awareness, sharing CVI-specific knowledge and transferring that knowledge to the child’s educational team rose from the conversations about how these women provide information about their child’s disability to their teams and how they navigate their responsibilities as a resource on CVI. The first step at the clinic was confirming the diagnosis. Once they started receiving treatments (therapies) from professionals with experience working with children with CVI, they became armed with some resources and knowledge. They took the knowledge from the clinical setting to the school and community settings to impart the information to general education teachers, classroom teachers, special education staff, and administrators.

Georgia went to Jenny’s classroom teacher with information on how to modify materials. Paula had a student action plan (Appendix I) for Grace’s staff at her school as well as provided resources, and Bridget called a reevaluation meeting after receiving the diagnosis to ensure Abby’s team would understand the implications of her CVI on her learning and special education plan.

Paula shared in her interview that she suspected another child attending her school had a CVI diagnosis but hesitated to share that knowledge. Georgia has spoken with other parents about it in terms of IEP planning challenges in the future, and Bridget’s information about ADHD misdiagnosis and overmedication of it showed her understanding of the very real possibility that children who have CVI could be misdiagnosed with other learning and attending disabilities.

Summary

Individual interviews with the participants in this study provided valuable insights into the experiences of the mothers of children with CVI, their challenges, and joys. All the participants painted a vivid picture of the challenges, concerns, love, and work that goes into caring for and caring about their children. Three categories and six sub-themes were revealed through the within-case and across-case analysis of semi-structured interviews: (a) CVI without a TVI--team CVI awareness, sharing CVI-specific knowledge, and transferring knowledge to the team; (b) the shifting roles of mothers--mother, advocate, professional; and (c) mothers' experiences within educational systems--navigating educational landscapes and apprehension and possibility.

In the proceeding section I will present the demographic information of the participants. I will discuss the medical documentation, functional vision evaluations, and CVI range assessments from the clinic and the IEP, evaluation, and other education-related documentation provided by the mothers. Discussions of findings, sub-themes, and categories will follow.

The following section highlights the educational and clinical documentation gathered for this study as well as the demographic information about the participants. Conventional content analysis was used to analyze the documentation within each case and then across cases and merged with participant interviews to provide confirmation of findings and answer the research questions.

Demographic Information

Demographic information was gathered via a phone interview conducted by the clinical research coordinator at the hospital. All of the participants lived in suburban areas approximately one hour from the children's hospital clinic. They all identified as female, and all identified as Caucasian. Two of the mothers were 41 to 50 years old, and one was 51 to 60 years old. One had a master's degree, and two had bachelor's degrees. Table 4 shows information gathered from the participants during the phone interview regarding their children. Table 4 provides children's demographic information, CVI diagnoses, and relevant evaluation excerpts for the purposes of providing an in-text reference for connections to data analysis, results, and discussion.

Table 4

Participants' Children's Demographics

Demographic Area	Jenny (Georgia)*	Abby (Bridget)*	Grace (Paula)*
Age	6	7	8
Grade	Kindergarten	Second	Second
School setting	Private	Public	Private
Age of CVI diagnosis	4	6	5
Years in special education	3	4	4
Early intervention	No	Yes	Yes
Being served by a TVI	No	Yes	No
Attended preschool	Yes	Yes	Yes
Educational placement	General education	Included a part of the time	Included a part of the time
Other areas of need	Feeding difficulties, communication delays	Motor and speech/language/ communication	Motor and speech and language/communication
Other areas of eligibility	Visual impairment	Multiple disabilities	Multiple disabilities
Services (IEP)	TVI/SLP/OT	TVI/OT/PT/SLP	SLP/interventionist (special ed background)
Private therapies	SLP/OT	OT	SLP/Counseling

*Mother's name in parentheses.

Document Information

Once participants completed their interviews, requested documentation including special education documentation, evaluations, and clinical assessments, and eye doctor reports and notes were shared and reviewed. The purpose of this review and analysis was to address the following research questions proposed in this study:

Q2 How does the mothers' understanding and knowledge of CVI contribute to the educational programming or services provided

Q3 How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?

I received clinical records including reports from the pediatric ophthalmologists, the CVI-specific and functional vision evaluations done by the OT and TVI staff, therapy reports, and reports for two of the participants who had neuropsychological evaluations at the clinic. The ophthalmologists' reports were integrated into the functional vision evaluations and CVI-specific evaluations. The neuropsychological reports conducted at the children's hospital tested IQ and all areas of development.

The participating mothers shared their child's most recent IEP. Two of the students (Jenny and Grace) attend private schools but have public school IEPs kept up to date. Bridget provided Abby's most current IEP as well. Paula provided Grace's most recent functional vision evaluation performed by the county vision professional (outside the clinic). Paula and Bridget provided the most recent evaluations done by the school district. Paula also provided the "Student Action Plan" specific to the private school Grace attends. This document outlined challenges, goals, and supports that provide her educational team with guidance on how to effectively instruct her and promote support for her disabilities (Appendix I). Learning media assessments were not conducted in the CVI clinic. These assessments are usually done by the TVIs in the school district; therefore, there was not information included in the documentation provided that recorded how the appropriate literacy medium was decided for each child.

In Jenny's IEP, braille was marked as not appropriate, and her evaluation was not provided. In Abby's IEP, visual impairment is not marked as an area of need, even though the entire document has references to her visual disability. This is an error, but because of this, there is no mention of a required learning medium. Grace's provided FVA did not show any information in reference to an LMA. In Grace's eligibility section where the adverse effects of CVI were noted, the report stated,

> [Grace's] CVI diagnosis, causes challenges with 2 dimensional images, struggles with movement as a distractor and complexity of classroom lessons, causing latency . . . she has trouble seeing items on a board or paper. She will need specially designed instruction to help her facilitate visual discrimination and comprehend classroom materials presented visually.

This information presents the difficulties Grace might have with materials. It is difficult to determine how the decision was made that she learns effectively through the use of pictures, visuals, and two-dimensional images without some kind of assessment of the most appropriate literacy medium.

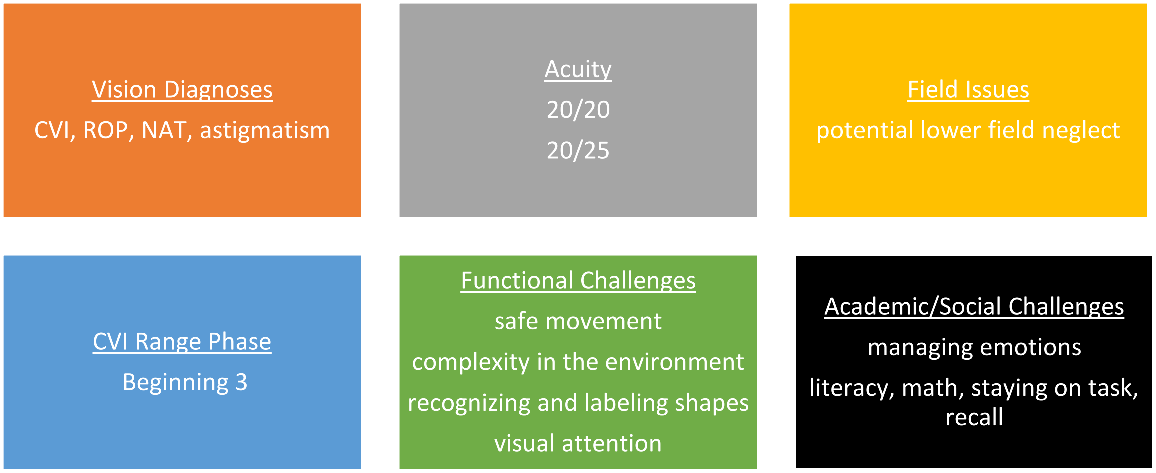
Cerebral Visual Impairment Profiles

Cerebral visual impairment profiles were created from the clinical documentation, both doctor and therapist's reports, and the CVI range and FVAs. The profiles are presented in Figures 4, 5, and 6. Neurological diagnoses are provided at the top of each figure so the reader can understand why the patient presents with CVI. As previously explained, CVI diagnosis is not based on one factor, but is determined by medical history, performance on visual tests, and lack of ocular diagnoses that would be responsible for any visual diagnoses. Neurological diagnoses were taken directly from the clinical paperwork provided. The purpose of the CVI profiles is that they can be used as a quick reference. For the purposes of this study, it was helpful to organize and present the information of children with medical histories that were complex. While none of the children in this study had severe or multiple disabilities, they do have complex histories in early childhood as well as prematurity (in two cases), and their young lives are already full of many clinical experiences. Tools such as the CVI profile can allow one to see patterns that link the severity of CVI (or the phase) with contributing diagnoses and functional challenges. These profiles are also useful to other practitioners when trying to communicate needs to teams and serve as helpful visual reminders. It is important to note that parent input is a large part of these assessments, as parents know their child best and have seen how they interact with the world at large, not just in a doctor's office. The profiles demonstrate the unique disabilities of each child, yet show the commonalities associated with brain-based visual impairment and the corresponding functional challenges associated with them.

Figure 4

Cerebral Visual Impairment Profile for Grace

CVI-specific diagnoses: prematurity, non-accidental trauma at infancy, brain anomalies (polymicrogyria, parietal encephalomalacia, white matter gliosis), cerebral palsy



Vision Diagnoses
CVI, ROP, NAT, astigmatism

Acuity
20/20
20/25

Field Issues
potential lower field neglect

CVI Range Phase
Beginning 3

Functional Challenges
safe movement
complexity in the environment
recognizing and labeling shapes
visual attention

Academic/Social Challenges
managing emotions
literacy, math, staying on task, recall

Figure 5

Cerebral Visual Impairment Profile for Abby

CVI-specific diagnoses: underdeveloped sections of the brain (pons), white matter abnormalities, gray matter heterotopia next to the left ventricle, slightly underdeveloped corpus collosum, cerebral palsy

Vision diagnosis
CVI, hyperopia, amblyopia

Acuity
20/20

Field Issues
lower field neglect

CVI Range Phase
Late 2

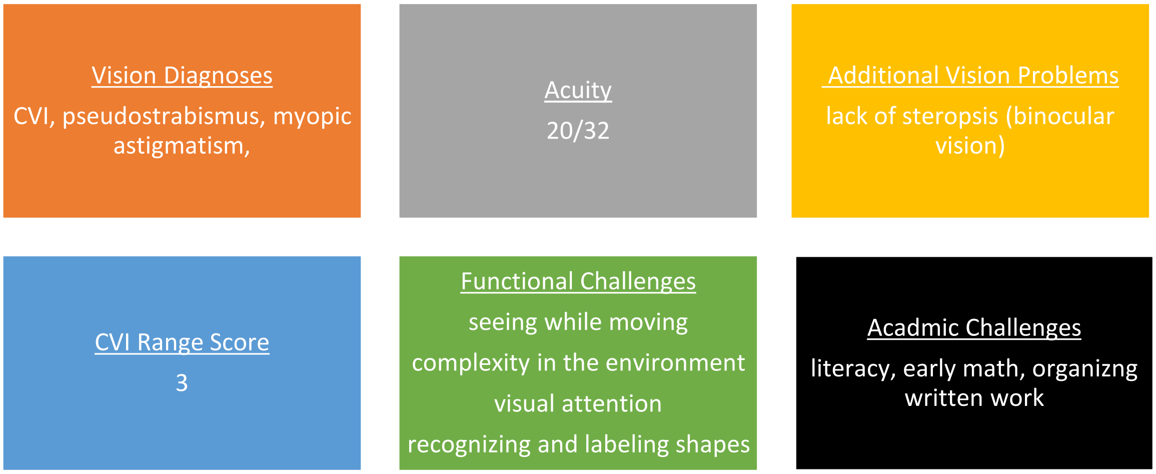
Funtional challenges
visual attention, safe movement

Academic Challenges
literacy
math, staying on task

Figure 6

Cerebral Visual Impairment Profile for Jenny

CVI-specific diagnoses: premature, stroke in utero (suspected), focal loss of cortical and subcortical white matter in the right posterior parietal, occipital, and posterior temporal lobes, scattered white matter abnormalities in both frontal lobes and around the ventricles.



Vision Diagnoses
CVI, pseudostrabismus, myopic astigmatism,

Acuity
20/32

Additional Vision Problems
lack of steropsis (binocular vision)

CVI Range Score
3

Functional Challenges
seeing while moving
complexity in the environment
visual attention
recognizing and labeling shapes

Acadmic Challenges
literacy, early math, organizng written work

Cerebral Visual Impairment Profile Summaries

Each child in this study has CVI because of the impact of injury and/or underdevelopment of their brains. Each child has additional issues with the way their eyes move. Jenny’s profile (above) shows that she cannot use her eyes together and has additional oculomotor issues related to the way her eyes are aligned as well as astigmatism which can make images blurry (note that visual acuities are all within normal ranges). Jenny’s glasses provide correction for her astigmatism. All these children also have similar functional challenges, and it is of note that all have difficulty with complex visual environments and sustaining visual attention. It is noted in the “Academic Challenges” that they all have difficulties with math and literacy for which maintaining visual attention is key.

Both Grace and Abby have CP, both have neglect in their lower visual fields, meaning they miss information in that area, and both have difficulty with safe movement through space.

Note that they both have functional challenges with safe movement, and this was also echoed in Grace's mom's interview and the information from Abby's IEP. Grace's mom mentioned her difficulties on the playground and moving in the hallways. This specific challenge of movement, coupled with difficulty with visual complexity in the environment, impacts the child in many educational and community settings.

The CVI Range scores on these profiles are expanded upon in the next section. Each child scores relatively high on the CVI Range assessment, and the score indicates that they use their vision for learning but require supports to deal with the challenges presented by their complex medical histories and profiles.

Clinical Reports: The Cerebral Visual Impairment Range

The CVI Range was developed by Roman-Lantzy (2007) to help practitioners understand the visual behaviors of children with CVI and how to target them through instruction, modifications, and adaptations of the sensory environment and learning and everyday materials. As explained in Chapter II, the CVI Range is an assessment of the 10 characteristics of CVI: (1) Color Preference; (2). Need for Movement; (3) Visual Latency; (4) Visual Field Preferences; (5) Difficulty with Visual Complexity; (6) Light-Gazing; (7) Difficulty with Distance Viewing; (8) Visual Reflex Responses; (9) Difficulty with Visual Novelty; and (10) Visual Motor. The Range is usually conducted by a TVI who gathers information from parent reports and observes and tests the ways in which the child interacts with the visual environment. The Range is scored according to three phases of visual functioning. Each phase contains specific visual goals that should guide interventions and environmental and material modifications. In the cases of the three children reviewed in this study, the CVI Range evaluations were performed by personnel in the clinic, OTs, and TVIs who work closely with the pediatric ophthalmology team at the clinic.

The results of each child's characteristics and findings from the CVI Range assessments conducted in the clinic are presented in Appendix G. All information is taken from the CVI Range assessments administered in the clinic. The details about the difficulty the child had within the area is explained below the graphic. This is to provide examples of what challenges these characteristics can present for those with the diagnosis.

Cerebral Visual Impairment Range Analysis

The CVI Range reports reviewed for this study were taken from the assessments taken in the clinical setting. These were administered by staff with experience and knowledge about CVI who work closely with pediatric ophthalmologists and other clinic staff. Conventional content analysis was used to discern the major characteristics and visual challenges each child has (within case) and the commonalities of those elements across case.

The CVI Range can be useful for discerning the specific behavioral characteristics these children have because of their CVI diagnosis. While the CVI Range is not a validated assessment tool (Chang & Borchert, 2020), it is a useful resource for instructional planning and environmental modifications. It is important that the assessment be done by someone who has knowledge of CVI and is trained to perform the assessment. Because the behaviors elicited by CVI can be subtle and very nuanced, observations must be noted. This, along with history-taking and asking the family questions about visual functioning in the home and community environments, can create useful pieces of information for educational staff and families. These students all scored on or around the same phase on the CVI Range. Phase 3 on the CVI Range indicates that the student demonstrates visual curiosity and spontaneously uses vision for most functional activities (Roman-Lantzy, 2007).

All the children in this study demonstrated associated difficulties with visual complexity, both relative to materials and the environment itself. The children were also all distracted by movement. It was noted in the clinical assessments that all three had difficulty maintaining focus on tasks, especially when those tasks were new and cognitively demanding. Children in this phase of CVI can have lower visual field neglect (Dutton et al., 2004) and difficulty with distance viewing in unfamiliar and outdoor areas. It was noted that Grace and Abby were documented with lower field neglect, and all the children presented issues with visual complexity in the distance. Each child demonstrated difficulty with distance viewing, not because of being nearsighted, but since the farther away visual information is, the more difficult it is to discern what you are observing because of the visual complexity of environments. The farther away something is, the more embedded in visual clutter it can appear and the harder it is to see. Both Abby and Grace demonstrated some difficulties with visual motor tasks, sometimes performing look and reach as separately executed functions. Jenny demonstrated difficulties labeling objects. When they were presented separately, she did okay; but once presented with animals in a more complex visual environment, she had difficulty discerning the visual details of the objects.

Both Abby and Grace demonstrated difficulty with visual latency. This is the lag time it takes for the sensory system to fixate on a visual target. This could be due to accompanying oculomotor issues. All three required visual models and verbal prompting to perform tasks during the assessment, and the assessors noted they would give up when the tasks became too challenging.

Individualized Educational Program Documentation

The participants in this study each provided their child’s most recent IEP. I used conventional content analysis to understand the categories as they arose directly from the text.

The categories will be examined in the Results section (which follows the IEP information). Each document was reviewed for parent input on their child’s visual functioning, needs, abilities, and any language as it relates to vision. I read the entire IEP and recorded my first impressions. I went back and reviewed the document again, paying specific attention to evaluation information inputted and whether it was also present in the clinical information. I returned to the IEPs and noted instances of vision supports within goals, vision-specific goals, modifications, supplementary aides and services, service delivery methods, service time, and whether visual challenges or supports were noted in present levels of performance in all areas.

These documents were analyzed within case--to discern the link between the evaluations and the supports included in the IEP specific to CVI. Across-case analysis was done to understand the categories across the children’s evaluations and ways in which these manifested themselves in the educational programming. I sought to understand the extent to which parent reports (from the document and interviews) assisted in the creation and implementation of educational programming. This analysis will be presented after the IEP documentation information below.

Parent Input

Parent input was taken directly from the “Parent Concerns” and “Strengths of the Students” sections in the IEP documentation. One of the first questions asked of a parent during the IEP meeting process is about a child’s strengths and interests. Special education is deficit-based, but this question sets the stage for the parent to provide input at the start of the meeting about the positive qualities their child possesses. Another question asked is in regard to parent concerns. Table 5 shows each participant’s input in their child’s IEP and/or evaluation, provided in the formal meeting setting with the special education teams. These are all taken from reports from the child’s public school district. All the mothers provided input to the staff during the evaluations done at the clinic. The information provided in those reports is included in the special education documentation as well. The mothers also contributed to the educational planning through their input during the evaluations. Given their unique experiences in the clinic and as taking on the roles of their children’s TVIs, it is not surprising that there are frequent mentions of vision-specific supports in these sections of the IEPs.

Table 5

Parent Input in Educational Documentation

Student	Document	Parent Input
Jenny	IEP	Concerns--from clinical documentation
		Progress or lack of progress in outside therapies, “Mother provided a functional vision assessment from ______ Children’s Hospital.”
Abby	IEP	Concerns: handwriting, increasing attention to task, be a reader, continue to enunciate and speak clearly, gain confidence and be more independent, follow directions.
		Strengths: kind, sweet, friendly, loves to play. Loves “Frozen” and music. Is a hard worker; likes to please people.
		Medical and safety concerns: information from clinic and concerns about spatial awareness and safety.
	Reevaluation	Requested reevaluation after CVI diagnosis.
		From the document: Abby’s mother requested this evaluation to determine if Abby’s educational needs have changed due to her diagnosis of CVI.
Grace	IEP	Concerns: schoolwork, lack of attention and understanding concepts and use of vision.
		Safe movement, playground safety.
	Evaluation	Parents are in CVI group, watching other is good learning. _____ reported she couldn’t see. Parents visited class and there was glare on the board and teacher corrected it. She is working on self-regulating and orange is her preferred color. Her teacher has put accommodations in place to help her.
	Student action plan	Strengths: determined, perseveres through difficult tasks with a positive spirit, kind and caring, tries to work on her own as much as she can, is able to identify when she needs help and ask for it, memory details of day-to-day events, self-advocate
		Mother inputted all vision related specific information, goals from public school IEP,

Individualized Educational Program Goals, Objectives and Supports

Individualized educational program goals that required vision or visual motor skills to achieve and supports provided are included in Table 6. Recall, Jenny and Grace are in private schools and do not have the support of TVI services. Neither has an active IEP, but Grace's visual needs are taken care of by her mother and her student support plan document (Appendix I). Abby is enrolled in public school, and her IEP is followed by her educational team. Abby has 30 minutes of TVI service a month. Jenny has 30 minutes of TVI service, three times per month, but doesn't currently receive any special education services, only outside therapies. Grace only has speech therapy three times a month and outside counseling as well as OT at the children's hospital clinic. Her IEP contains only a speech goal and no service times because of her parents' choice to reject the IEP in the public-school setting.

Table 6

Student Goals and Supports

Student	Goals	Supports as Related to CVI
Jenny	Fine Motor *When presented with whole words or letters, Jenny will correctly identify them 80% of given opportunities over three consecutive sessions measured twice per month by a teacher-made checklist specially designed instruction.* Benchmarks: *1.When presented with a bubble words or letters, Jenny will correctly identify them 40% of given opportunities.* *2. When presented with bubble words or letters, Jenny will correctly identify them 60% of given opportunities.*	Extended wait time Use of a black background Spotlighting Repetition Modeling Hand-under-hand guidance Direct instruction on salient features
	When presented with writing and cutting tasks, Jenny will complete writing and cutting tasks with 80% accuracy across 4 consecutive sessions as monitored by classroom staff.	Verbal/visual/tactile prompts and cues, peer and adult modeling, visual motor activities, visual perceptual activities
Abby	Fine Motor *During small group instruction incorporating visual accommodations and modeling skills, Abby will legibly accurately complete a handwriting or cutting task, given no more than one to two adult prompts, in three out of four trials by the end of the IEP*	“Incorporating visual accommodations and modeling” CVI supports in specially designed instruction--all areas of deficit
	Math *In a small-group setting, Abby will identify 4 out of 5 numbers between 1 to 20 that are greater on 3 out of 4 performance assessments by the end of the 2020-2021 IEP.*	Visual and verbal cues and accommodations Multi-sensory supports Small-group instruction
	Gross Motor *Abby will increase her ability to independently maneuver through our educational environment in order to access our educational materials and curriculum with demonstration and verbal cues 4 out of 5 opportunities by the end of the 2020-21 IEP.*	
Grace	Communication *Using a sequence of colored pictures/photos, Grace will use contextual sentences to describe the events with 80% accuracy over two measures taken 2x a month using a frequency count.*	Using visual and graphic organizers

Document Analysis

In the preceding sections, I have illustrated the nuances of each child's CVI diagnosis and the resulting areas of need. I have included the CVI-specific information from the student's clinical and educational documentation. I have highlighted relevant information from the documentation and presented it in visual organizers in the section above. Conventional content analysis was used to create categories of the elements within the documents of each case and then across cases. Next, I will analyze the themes presented in this study and how they merge with elements of the special education documentation and evaluations and how the interviews provide insight into the information contained in the documents. Three categories and six themes arose from categories across the study and included: (a) the shifting roles of mothers--mother, advocate, and professional; (b) mothers' experiences within educational systems--navigating educational landscapes, apprehension and possibility; and (c) CVI without a TVI--team CVI awareness, sharing CVI-specific knowledge, and transferring knowledge to team.

Sharing Cerebral Visual Impairment-Specific Knowledge

Jenny and Abby had information in their IEPs and, in Grace's case, a "Student Action Plan" regarding modifications and accommodations as supports for learning to specifically address her CVI diagnosis. Supports frequently appeared in the goals themselves in the forms of visual presentation (bubble words), visual and verbal modeling, visual accommodations, and, when areas of Specially Designed Instruction were indicated, CVI supports were also placed so practitioners would provide them their instruction areas as well.

In Jenny's IEP, there were 17 CVI-specific supports in the "Supplementary Aides and Services" portion of her IEP as well as a "Program Modification" that stated, "TVI will collaborate with the team to ensure Jenny's visual needs are met and that she has access to materials adapted for her level on the CVI range."

The one goal that was specific to CVI only was Jenny's "bubble letter goal." This is a TVI-created way to teach visual site words to children. According to the website, Paths to Literacy, in "bubble lettering," the actual letters are not written out, but rather the outlined shape of the entire word (all letters together). They are usually red with a white border, or sometimes no border (https://www.pathstoliteracy.org/technology/word-bubbling-tool-teaching-students-cvi). This "intervention" is not evidence-based. Two of the mothers mentioned it in their interviews.

On her "Student Action Plan" (Appendix I), Grace has goals not included on her public-school IEP. These goals were not included above because this is not an official IEP document, but it is of interest. As part of the data included in this study, this document is a representation of the parents' knowledge of CVI integrated with the work of her education team at her private school. Reading, writing goals, and solving math problems are all included. This document has 27 CVI-specific "Recommended Accommodations." Many of them are very specific such as, "Be aware of the hierarchy of image complexity and provide [Grace] with the most realistic images possible for initial instruction. Add color where possible to facilitate discrimination."

In Abby's IEP, there were 33 instances of CVI-specific accommodations. In her evaluation, there were 52 instances of the word "CVI." Her supports for "Specially Designed Instruction" are included in Table 6 above.

In all the documentation, CVI information was featured throughout. In Abby's OT report, the teacher shared how Abby provided her own visual accommodations like telling her therapist a bold line was easier for her to see, and it was noted Abby was more accurate when writing letters when given a visual model. The goals featured in Table 6 above also show that the practitioners also integrated visual supports in the student’s goals.

Transferring Knowledge to the Team

As a result of receiving the clinical information, the OTs (in particular) echoed much of the clinical evaluations in the sections of the IEP they were responsible for. Fine motor goals contained visual supports. Visual motor tasks incorporate the use of both the eyes and hands together, and it makes sense that the team incorporated the information. The clinical assessments are presented throughout the entire evaluations (Grace and Abby’s; Jenny’s was not available). Medical reports are required information for student evaluations because they confirm diagnosis of disability.

Grace’s TVI consultant from the state school for the blind wrote a lengthy evaluation including information she gathered from classroom observations and observations during an occupational therapy session. She included the CVI Range scores and information from the clinic on her report and also wrote specifics on her observations of Grace’s CVI and how it impacted her ability to perform visual motor tasks. The TVI also incorporated information that Paula gave her. The TVI also provided a wide range of recommendations on her report; some were gathered from the clinic, and some were original. These were all incorporated into Grace’s “Student Action Plan” (Appendix I) that is where the “Be aware of hierarchy of complex imagery” accommodation is featured. The TVI relayed that she told Grace’s mother that CVI can present like ADHD in some children. The hearing specialist also echoed this at the meeting regarding auditory processing disorders.

Most of the practitioners included their own observations and assessments on the evaluations as well as clinical information that was pertinent to their areas of expertise. Aside from information on diagnoses and the CVI Range specific information, other information about the child's vision (the functional vision evaluation portion) was not specifically included in the evaluations or the IEPs. These are not areas of need, but they might be included as how the child functions visually or how some aspects of the child's vision have developed over time.

Abby's TVI included all the information from the CVI Range assessment at the clinic, her own observations during a PT session, and a summary that includes some contradictory information from the clinical information. For example, there is a reference to "reduced visual acuity," yet, the clinical information on acuity shows nearly perfect visual acuity.

Because the mothers attended appointments at the clinic with their daughters, the clinical information (most notably about the CVI Range) includes information that the mothers provided to the staff at the clinic. That information was then provided to the educational team to use in the reports. The mothers are a major source of information on their daughters in all aspects of this study.

Cerebral Visual Impairment without a Teacher of the Visually Impaired

Grace's TVI consultant shared information cautioning the use of two-dimensional images for her learning needs. The instances of visual information, accommodations, and supports in these documents attest to the wide spectrum of needs that accompany a CVI diagnosis at this high a level of overall functioning. In other words, these children are identified with mild CVI, and they are academic. This indicates that they need high levels of accommodations because, unlike children with severe multiple impairments, developmentally, they are doing some of the work that is expected of children their age, but it is modified. That work, especially in terms of literacy and math, is visual. The implications of this are that many adaptations must be made. Even in these children, who are all in a relatively same space on the CVI Range and in terms of visual functioning, have unique needs. What works for one might not work for another in terms of adaptations. While it is so encouraging that all these visual supports are in place for these children, the supports are not always specifically explained or within the recommendations. The two private school students have no TVI. Abby does, but the TVI sees her on a more limited basis than her other therapists and teachers. The TVI consultant for Grace provided comprehensive information on how to provide her with support, but how can Paula interpret all of that without the same level of expertise? In the interview, Paula said she was told she could reach out and call at any time, but is a phone conversation going to provide in-depth guidance on the 27 CVI-specific supports on her “Student Action Plan” document? Who is responsible for creating and providing supports when they are related to visual impairment?

Conclusions

In this chapter, I have presented a large amount of information gathered from the clinical and educational documentation. The participants in this study provided a window into their world where they care, advocate, and teach others about their children with CVI. I presented the information gleaned from the documentation as organized, visual references. I presented the themes that emerged from the educational documentation and analyzed them across cases.

In the next chapter, the results of this qualitative, multiple case study are presented. Data will be triangulated to present comprehensive answers to the research questions.

CHAPTER V

DISCUSSION

Cerebral visual impairment is the leading cause of pediatric visual impairment in the developed world and is becoming increasingly more common in the developing world as well (Bosch et al., 2014; Dutton & Bax, 2010; Hoyt, 2007; Kong et al., 2012; Kran et al., 2019). Cerebral visual impairment is a visual condition of neurological origin that originates in various areas or networks across the brain and causes impacts to the processing of visual information (Lueck & Dutton, 2015). The condition is diagnosed when there is vision loss that is “greater than expected based on the degree of ocular pathology” (Chang & Borchert, 2020, p 708). Causes of CVI are great in number and include perinatal or postnatal hypoxic-ischemic damage, hydrocephalus, and seizures (Chang & Borchert, 2020). In this study, all three participants had CVI resulting from neurological impact in infancy and/or during prenatal or perinatal development.

The most comprehensive approach to establishing diagnoses and understanding CVI in children is creating a knowledge base for families and professionals that can be used to provide resources and information. This knowledge base has been developed over the past 40 years, but still, it continues to morph and change as the field learns more about the brain, cognitive impairment, and the experiences like those shared in this study.

In the 14 years I have worked as a TVI, many of the students and young children on my caseload have been children with CVI. Over the years, as I was exposed to more information on

CVI and tried to effectively serve the children on my caseload, I found that there was a dearth of information and comprehensive assessment practices for these children. This inspired me to get involved with researchers and experts who study CVI, and I came to realize that understanding CVI is really a balance of digesting clinical information and functional visual information and synthesizing them to understand how CVI affects access to learning.

Findings

The purpose of this qualitative multiple case study was to examine the educational programming of students with CVI to determine if their needs, as perceived by their mothers and set forth by their clinical and educational documentation, are represented in their academic/functional goals and programming. Semi-structured interviews were conducted with three mothers of children who had a CVI diagnosis and who were all patients at the same children's hospital clinic in a major city in the midwestern United States. The mothers shared their experiences of receiving a diagnosis at the clinic and the journey that followed for them and their child. To understand the participants' experiences at the clinic, in special education meetings, and how the needs of their child's visual disability are met in the educational setting, the research questions were developed:

Q1 What are the mothers' experiences of their child's special education programming and goals for meeting their CVI-specific needs?

Q2 How does the mother's understanding and knowledge of CVI contribute to the educational programming or services provided?

Q3 How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?

The results from this study revealed valuable information on the multitude of roles that mothers play across the physical, social, and emotional spaces in the lives of their children. Since comprehensive assessment and specific programming is crucial for the success of students with

CVI, the results of this study helped to construct a more comprehensive picture of the outcomes of clinical and educational assessment and opportunities for collaboration with parents and families of children with CVI. It also provided a better understanding of the challenges families face, lack of resources on CVI, and a lack of qualified personnel in the field.

Each participating mother made choices for her child on what she deemed best, but these decisions are complex. Each participant’s experiences parenting their other children, being part of specific communities, and attending the clinical exams and assessments with their daughters, provided them with strong opinions on how to advocate and provide information on their daughter’s diagnoses. The fact that both the mothers of children enrolled in private school played the role of their child’s advocate and vision professional was not surprising, given the placement. But the extent to which they had to provide support and resources emerged as a common theme across the cases. Their experiences revealed an awareness about the lack of vision personnel and provided insight into their shifting roles in the public and private school settings. Findings from this study also show that with adequate and comprehensive evaluations and assessments, teams who serve children with CVI can develop comprehensive plans that support the child’s learning and target their visual challenges. These findings support what the literature in this area suggests, that structured history-taking and comprehensive clinical evaluations including neurologists, neuropsychologists, and ophthalmologists paired with targeted teaching of teachers and parents about the visual challenges of the child is necessary for managing CVI. (Chang & Borchert, 2020; Chokron et al., 2020; McConnell et al., 2021; Zihl & Dutton, 2016). The alternate explanation is that it is still unclear who is responsible for teaching staff how to implement the supports if there are no personnel with qualifications in visual impairments to do it. In this study, that job fell to the participating mothers. This study also provided some interesting insight into how educational programming is developed for children with CVI and how visually demanding components are presented as ways to achieve goals and make progress without indication that any learning media decision has been made in the documentation. For example, Abby has a goal to “decode 4 out of 4 CVC words,” but there is no support within the goal to indicate how these words are presented. Her IEP mentions multi-sensory presentation once (in relation to fine motor present levels) but makes no indication of any visual supports within the goal except general “slant board” and “black background.” Grace has options for listening to stories on audio in her “Student Action Plan,” but the other two students do not have any references to auditory learning in their documents.

Restatement of the Research Problem

Cerebral visual impairment as a cause of visual impairment in pediatric populations is increasing. This increase is attributed to advancements in medical technology used to treat preterm and at-risk infants who are surviving at increased rates in both the developed and developing worlds (Bosch et al., 2014; Dutton & Bax, 2010; Hoyt, 2007; Kong et al., 2012; Kran et al., 2019). The first step in targeting CVI is receiving a diagnosis because children with CVI require specialized strategies for comprehensive visual evaluation (Chang & Borchert, 2020). Experts and professionals in the field of blindness and visual impairment have worked for the past 30 years to understand and serve students with CVI, and we are still developing and attempting to validate objective measures of assessment and standardize care for these children. Research has shown that CVI can be managed effective and improved upon only if comprehensive assessment and programming are instituted at the earliest age possible (Dutton et al., 1996; Lehman, 2012; Ortibus, Laenen, et al., 2011). The best approach is to review comprehensive ophthalmological exams, neuroimaging, and medical records as components of a comprehensive history-taking strategy that includes family input as well. This comprehensive assessment also includes specialized assessments performed by vision professionals such as formalized FVA and LMAs. These are conducted by TVIs who are specialized in determining functional vision and how the child accesses and uses sensory information in the environment.

Part of the comprehensive support system problem is evidenced in this study. The knowledge base of professionals when it comes to effective and comprehensive assessment and instruction of students with CVI does not always meet the needs of this unique population. In Mazel et al.'s 2019 survey, the research team found the majority of teachers surveyed felt they had little or no training in their university programs in the proper assessment and instruction of students with CVI. In their survey of parents of children with CVI, Jackel et al. (2010) uncovered that parents had to do research themselves to get supports and services to meet their child's intervention needs. In a more recent study, Goodenough et al. (2021) found (through their series of semi-structured interviews) that parents articulated the importance that the professionals assessing and working with their children comprehensively understand the complexities of CVI.

The purpose of this qualitative multiple case study was to examine if the educational needs of these students with CVI, as perceived by their mothers and set forth by clinical and educational documentation, are represented in their academic and functional goals and programming. Three mothers of children with diagnoses of CVI whose children all attended the same specialty CVI clinic at a children's hospital in a major midwestern city were interviewed about their experiences in the clinical and educational settings. Semi-structure, open-ended interview questions were used to collect responses from the mothers on their experiences of receiving CVI information in the clinical setting and contributing that knowledge during IEP meetings and evaluations. Interviews with the mothers revealed themes regarding their experiences working with the clinic, their children, and as an educational team member. Clinical and special education documentation was reviewed and analyzed as the key to understanding CVI is merging and synthesizing information from both settings to fully understand the child's CVI. Data from the interviews and documents were analyzed to determine answers to the research questions.

Three official categories emerged from the data: (a) the shifting roles of mothers; (b) mothers' experiences within educational systems; and (c) CVI without a TVI. Data also brought forth three sub-themes: (a) the shifting roles of mothers--mother, advocate, professional; (b) mothers' experiences within educational systems--navigating educational landscapes, apprehension and possibility; and (c) CVI without a TVI--team CVI awareness, sharing CVI-specific knowledge, and transferring knowledge to team.

Answering the Research Questions

Transfer of Cerebral Visual Impairment Knowledge

Q3 How are CVI vision/sensory specific needs reflected or recorded in clinical and educational assessments and IEP documentation?

Parents provided information in the clinical setting that was then transferred to the clinic staff to record on the CVI Range assessment and notes about visual functioning. The comprehensive clinical reports were wholly integrated into the evaluations and subsequent IEP documents. The two themes of sharing CVI-specific knowledge and clinical transfer of knowledge to teams specifically target parent input to the clinic staff, clinic input for the educational team staff, and parent input to the educational team staff. These transfers of knowledge did not happen magically. Parent knowledge provided at the clinic was integrated into the notes and assessments. The assessors relied on the history-taking provided by the parents in the form of questionnaires. The pediatric ophthalmologist provided the results from the functional vision evaluations including information about visual acuity measurements, visual fields, eye movements and alignment, refraction and examination and dilation of the fundus, and contrast sensitivity (K. Castleberry, personal communication, August 4, 2020). The clinic's OT and TVI staff members performed the CVI Range assessment, again integrating parent reports into the CVI Range assessment when it was required, or they needed more information that was difficult to test in the clinical setting.

The information from the clinic was transferred via a special education team's request for records or from the parent sharing the information directly with the team. The method of how the special education team received the documents was recorded in the documents. In Abby's case, her mother was the communicator of the CVI-specific information. Bridget shared the diagnosis received at the clinic and requested a reevaluation to see if her daughter's educational eligibility and programming would be amended with this new information. Federal law requires that a reevaluation be administered if a parent requests it of the team. [34 CFR 300.303] [20 U.S.C. 1414(a)(2)]. I believe the experience of receiving the CVI diagnosis and understanding how it affected her daughter's behavior and academic abilities allowed Bridget to transfer her knowledge from the clinical setting to the educational setting in this instance. All of the mothers in this study shared that they stayed on top of their child's IEP and shared that they felt like a member of the student's educational teams within their schools.

Once clinical information was received by the educational teams, they used it in addition to their in-person observations and assessments of student performance of activities within their respective areas of expertise. This demonstrated the clinical transfer of knowledge to teams which aided in the development of the child's IEP.

In technical terms, the mothers provided the documentation from the children's hospital clinic. Both Abby's and Grace's mothers mentioned paying attention to tasks in their concerns about their children. Jenny's mother's concerns were taken from the clinical documentation. The clinical transfer of knowledge is also an exchange between the parent and the therapists during outside therapy sessions. During school-based therapies, parents cannot share in the experience; but in a private therapy session, they can. Abby's mother, Bridget, relayed that while the current Covid-19 pandemic was a disruption to their lives, she learned much more during her daughter's school therapies and how they worked with Abby because she was able to attend them virtually.

The transfer of knowledge from the clinical documentation was integrated into the evaluation and IEP in the medical background sections, and I also noted that some of the "parent concerns" section of the IEP were taken directly from the clinical documentation. Parent input at the clinics also showed up in the "safety concerns" section of Abby's IEP.

This transfer of knowledge also emerged when clinic staff visited the student's school to provide a presentation on CVI to the staff. Abby's mother questioned if it was well received, but the other mothers thought it was helpful; but unfortunately, it had only happened one time, after their child received the CVI diagnosis. In my talks with the clinic staff, they relayed that their TVI on staff calls educational teams and attempts to provide them with insightful information, but she is not a staff member at a public school.

Overall, CVI needs, and sensory-specific needs were reflected very comprehensively due to the transfer of clinical knowledge and its utility in helping to understand the student's needs in their educational setting, particularly with this new diagnosis. The clinical assessments (FVA, CVI Range, and neuropsychological) all contained multiple pages of recommendations for the education and home settings. These are the CVI needs as they are reflected in the documentation, but they also carried over to the IEP documentation when the team deemed them relevant to certain sections. The neuropsychological recommendations were not utilized as readily as the CVI-specific ones. The neuropsychological evaluation contained information on all developmental areas, and it could be that the other practitioners had specific assessments of their own and so used that information instead.

Shifting Roles of Mothers

One theme that emerged as a particularly specific answer to Research Question 2 was the shifting roles of mothers as advocates and professionals.

> Q2 How does the mothers' understanding and knowledge of CVI contribute to the educational programming or services provided?

The cases of the mothers in this study told the stories of how they acted (to the extent they could) as their child's advocate, vision professional, IEP team lead, and caretaker.

In general, mothers of children with disabilities take on multiple roles and responsibilities in the lives of their children (Stoner et al., 2005). Research in autism spectrum disorder, for example, has shown that parents engage in multiple roles in their interaction with education professionals and that these relationships represent a complex landscape (Stoner & Angell, 2006). These authors learned that mothers routinely engaged in the roles of negotiator, monitor, supporter, and advocate. Their trust in education personnel affected the extent of their engagement within these roles. Just as Paula and Jenny have spent time in their daughter's school environment to teach personnel about CVI, Stoner and Angell (2006) found that mothers spent time in schools to monitor their children's education and they "engaged in numerous roles as they interacted with education professionals" (p. 185). Role shifts or role releases are common in special education where an individual in one discipline might provide instruction to another individual in a different discipline so team members can provide holistic support to each other and the student (Jager & Moser, 2000).

The mothers that were present at the CVI clinic at the children's hospital contributed to their child's IEPs. They provided resources and information to their child's teachers. Even if that teacher had background as a special educator (in Grace's case), the information about CVI still had to be shared. Paula's knowledge of CVI lead her to buy resources Grace would need and to develop a full report on how she could be supported in the classroom (Appendix I). In the very limited studies done in the area of parents of children with visual impairments and how they view services and information provided from clinical staff on their child's visual disability, Lennon et al. (2008) found that parents can be highly satisfied with written reports containing information related to their child's diagnosis. These reports contained relevant practical information for both the parents and teachers.

The mothers in the private school settings both have taken it upon themselves to essentially play the role of their daughter's TVI. This is a major finding of this study. This is not a surprise necessarily, because our field has such personnel shortages. But, contributing their knowledge about CVI to school teams and personnel is a big burden for these mothers who shared they are not sure they are doing it the right way or understanding it completely themselves. This makes sense, because even as an individual who studies CVI research, I do not think I will ever fully understand it. I have the training and resources, and I still struggle.

While understanding and knowledge contribute to the educational programming, it is also revealed within the category of the mother's experience within the educational system and its subthemes of navigating educational landscapes and apprehension and possibility. The interviews revealed the overwhelming responsibility having the knowledge of such a complex disability and worrying if you are doing things correctly and if you are doing enough for your child. Paula explained her frustrations during our interview, “You know it’s like every educator, you put your head on your pillow and did you do everything for every child.”

While the mothers are doing all they can for their child, they are struggling with the lack of resources on CVI. They are voicing that they might be able to contribute more understanding and knowledge so their children can be successful, but they need resources and support. Studies reviewed have shown that having a child with visual impairment can bring the parent anxiety about the visual condition with varying degrees of association between anxiety and the parent’s knowledge level about their child’s visual disability (Lupón et al., 2018). A 2010 study conducted that interviewed parents of children with autism spectrum disorder (Dabrowska & Pisula, 2010) showed that maternal stress was related to the level of their child’s social skills.

The literature in special education research has shown that mothers exhibit more parental stress (mothers of children with autism spectrum disorder) than fathers (Dabrowska & Pisula, 2010). It has also shown that mothers have relationships that support advocacy when there is open communication with their child’s educators and their feelings and concerns are validated by those educators as well (Stanley, 2015).

The possibility that emerged from the conversation with Bridget about her relief when Abby did not receive an ADHD diagnosis (because she was diagnosed with CVI) was palpable. This emerged as possibility through disability. Even though CVI was an unknown, Bridget was able to articulate the differences between ADHD and CVI and demonstrated an understanding that the experiences she had with one daughter with a disability would not be the same with Abby. Through the story she shared, Bridget’s shifting her role to advocate for her daughter also emerged, making the decision to not put Abby on ADHD medication and rely, instead, on the CVI supports that are in place for her at school, home, and the clinic.

One of the first steps to services can be receiving the CVI diagnosis. Goodenough et al. (2021) found that parents of children with CVI communicated that "early screening or assessment was described and vital to identify and manage CVI immediately" (p. 4). All the participants suspected there was something wrong with their child. The diagnosis in the clinic is evidence of CVI- and vision-specific sensory needs reflected in clinical documentation. As mentioned earlier, the recommendations provided in the documentation reflect the myriad of ways CVI challenges can be addressed. The purpose of the IEP goal is to target areas of need created by disability. Needs are further reflected by the CVI-specific supports written into the documentation to support the goals and help the child succeed.

Review and analysis of the educational documentation revealed the category CVI without a TVI, which emerges in the interview themes of sharing CVI-specific knowledge and transferring that knowledge to the team through promoting their awareness of CVI. These help to answer the following research question:

> Q1 What are the mothers' experiences of their child's special education programming and goals for meeting their CVI-specific needs?

This question is the most difficult one to answer. It is not as straightforward as the other research questions and is not as directly answered in the interviews or documentation. As I uncovered the themes for this study, it appeared that though the mothers felt their daughter's teams were doing a good job of meeting their needs (initially, when I asked the question), that apprehension emerged later in the conversation.

Paula stated that she thought her team was probably not meeting all her daughter's needs, "I don't know, I, I guess, if I was given it on a scale of 1 to 10, I feel like maybe a 6." But she had made the choice to send her to her private school. It was personal, and she also wasn't convinced she'd receive vision services in the public school setting anyway.

Jenny's mother thinks her team does a good job as well, but she has not been in the classroom, and she does not know what sort of support she is receiving specifically right now. But she knows Jenny is happy and excited to go to school and that she is making progress. Abby's mother was very honest when asked whether she thinks Abby's educational team meets her CVI-specific needs, "I think they're doing what they can with what they understand." Later in the interview, though, she relayed that she should probably do more to figure out what the vision teacher does and check in to see how much support she is getting related to her CVI. As the mothers have yet another role to fill as they navigate the educational landscape, they trust that needs are being met, and they are wondering if they are the ones charged with meeting their child's needs, are they doing it right, are they doing enough?

Through analysis of the special education documentation, the category of CVI without a TVI emerged as a logistical probe. If Grace has 27 CVI-related supports and accommodations on her "Student Action Plan," but no TVI, how are her needs being met? Maybe the "6 out of 10" answer reflects that. Jenny's and Abby's mothers seem accepting of the services they receive, but they also understand that there is a lack of resources. They both commented that the classroom teacher is really the one who is with their child and that the TVI would not or does not have a very consistent presence. There are numerous CVI supports throughout the documentation, but there are limited services from TVIs. Research shows that even with personnel in place (Mazel et al., 2019), those personnel are not necessarily trained to meet the needs of children with CVI. Personnel preparation has been an ongoing problem for years in the field of educating students with blindness and visual impairment. It continues to be an ongoing issue for a variety of factors including funding, qualified candidate recruitment, and a retiring work force (Pogrund, 2017).

The children in this study all represent a population of students with mild CVI. They do not have severe additional disabilities, but they have academic challenges, and their educational plans primarily include a constant flow of visual information in the environment as they go about their school day and studies. Their educational plans are very much predicated on their success in modified academic tasks. Even speech production goals have a visual component. More than 50% of the surface of the brain is used to process visual information (Hagen, 2012). While the plan is in place to meet their CVI-specific needs, how do the mothers know those needs are being met? Perhaps because these children all receive the outside therapies, their mothers are also more confident that their needs are being met in the clinical setting. Though we specifically talked about whether their child's needs were being met, they were somewhat being met through the mothers themselves (acting as the vision support by sharing information with the teacher and advocating for resources).

Meaning and Significance of the Study

To my knowledge, this is the first known qualitative multiple case study to evaluate the experiences of mothers of children with mild CVI who have all attended the same clinic where their children underwent assessment and received services. Because of the heterogeneity of the population of children diagnosed with CVI and the barriers of doing research with large medical institutions, it is difficult to conduct even a small study like this one. There were no studies that attempted to bridge clinical experiences and the experiences as a parent of a child with CVI. It is also not common to find pediatric ophthalmologists and therapists who provide the high standard of care that the individuals in this special clinic do. But the design of this study and the data it collected are most important because it is only through very comprehensive assessment that we can really meets the needs of children with CVI. Parents play a very important role in this as the individuals who tell the medical professionals about the child. At the children's hospital's cerebral palsy clinic, children are brought in and screened. If the staff suspects CVI, they alert their colleagues and have a conversation with the parents about the child's behavior. Each participant in this study went through this process, and the importance of that moment when their child's CVI was diagnosed cannot be overstated.

Vision is fundamental to learning, and learning is the main goal of education throughout the lifespan. There were no other studies that reviewed educational documentation in conjunction with clinical documentation and analyzed the content of those artifacts for clues on how one informs the other. As a field, we do this as TVIs all the time, but it is unusual to get so much information about a child's CVI from an eye doctor or clinic, and this is very helpful when creating an educational plan. It is ideal to have reports on specific neurological diagnoses: "Early brain damage is commonly diffused, so tends to affect multiple brain functions, leading to associated neurological disorders including epilepsy, intellectual disability, and CP, which can compound the deleterious effects of CVI on development" (Chokron et al., 2021). The children in this study all suffered brain damage in early development, and it would be very easy for them to be misdiagnosed as having other learning disabilities because of the problems associated with the manifestation of these problems. Recall that while they have these challenges, there are no problems with their eyes, and only one of them wears glasses.

A recent study (Williams et al., 2021) has identified that the number of children attending special schools for learning difficulties who also have CVI may be greater than 50% and calculated at least 3.4% of children who are affected go unidentified (Cavezian et al., 2010;

Williams et al., 2021). This is the reason why this study can contribute to the field of serving students with CVI; there are many children out there who need help, but in order to help them, we have to work together with families, doctors, educators, and therapists.

Implications for Practice

Teachers of the visually impaired and other professionals in the field of visual impairment understand the importance of the categories and themes that emerged from this study: (a) the shifting roles of mothers--mother, advocate, professional; (b) mothers' experiences within educational systems--navigating educational landscapes, apprehension, and possibility; and (c) CVI without a TVI--team CVI awareness, sharing CVI-specific knowledge, and transferring knowledge to team.

Students presented in this study are most likely the ones that we do not serve. Chokron et al. (2021) stated that the result of this type of mild brain injury in children can have numerous educational and behavioral consequences. These challenges can include cognitive, motor, social and learning development (Chokron & Dutton, 2016). What would have emerged from the interviews if these parents did not have their experiences in the clinic? Understanding the clinical information and being able to administer comprehensive assessment (as was done in the clinic) are invaluable in the context of the child's special education programming. We can help students and parents navigate educational landscapes by supporting the work they do every day through recognizing they are the individual that lives with and cares for the child and also the person who can give professionals the most information about the way they use their vision. Even if a parent cannot articulate what is going on visually, they still provide insights about the child's functioning as they tell you their stories.

The themes within the category “CVI without a TVI” asked the question of how comprehensive services are provided (i.e., all that is recommended in the clinical and educational documentation) with limited TVI services. Is it on the other practitioners to understand CVI so well that they should be able to implement all the supports for goals and instruction? Or are the supports all simple enough that they are easy to figure out and administer? Perhaps we should be looking at how many supports educators of students with visual impairments recommend and how many of them are useful enough for the child to demonstrate success. What parameters do we use to evaluate this?

The third implication is the alarming lack of information on the child’s preferred sensory channels which should be determined through the LMA. The LMA process should address students’ immediate and long-term literacy requirements, including Braille (Rosenblum et al., 2021). It is a federal requirement that all students with visual impairments be provided instruction in Braille, unless the educational team, through assessment, determines it is not appropriate (IDEA, 1997, 2004). The LMA is the “assessment” in that last line. The intent of the LMA is to determine the student’s literacy mode.

Traditional reading (with visual modifications) goals are the focus of each of these students’ IEP goals. It is important to understand the myriad of visual functioning requirements for reading in a typical way. Reading involves the efficient use of the central visual field, but it also involves other visual fields as well (Chokron et al., 2021). Attention in reading skills is a crucial component, as is the ability to see all the letters on the page at once, and the inability to recognize syllables, single symbols, and words is clearly a major challenge (Chokron et al., 2021).

These students might not require braille. This is a topic for further discussion, as learning braille requires intact spatial recognition and abilities. As a field, though, we need to investigate how beneficial it is for children like the ones in this study to learn by having to use their vision all the time in every daily task. The LMA helps us to decide which sensory channel the child uses most efficiently: auditory, tactile, or visual. But we do not have to pick just one sensory channel. I conclude there is a sense that if a child's eyes appear normal, they must use their eyes well. We must remember that when we talk about CVI, we are talking about the use of the brain, not the eyes. Each of the children in this study had many visual supports, but that is because all their work was visual. If you are 8 years old and still not reading, even when provided all of the interventions at the educator's disposal, perhaps it is time to re-evaluate.

I was surprised by the lack of resources the mothers in this study experienced. I think, as professionals, another implication is that we must provide more real perspectives to parents about what CVI is. We must help adults with CVI share their stories and experiences about what it is like to live with CVI. We tend to create little books with bright red bears and send a link of the file to parents to print for their child, but we need to do more. The mothers seemed to like the resources where an adult relayed what their experience with CVI was like. This implies that we could work harder to link adult individuals with CVI to our school-aged populations to develop networks of support.

The results of this study raise considerations for our field. As we begin to learn more about the brain, have access to more refined brain imaging techniques, and have more resources devoted solely to CVI, we need to return a bit to the basics of understanding sensory impairment and its effects on learning and functional challenges and how we might do better. Although research is now reaching us at a faster and faster pace, there is still no standard way to teach

TVIs all the facets of this complex disability. We must adequately prepare our teachers for the largest population of students that they serve and work with medical professionals to redefine the way we work with this population.

Future Research

Just as it was difficult for the mothers in this study to articulate what was wrong with their children, it is even more difficult for children to recognize that their vision is disordered. Cerebral visual impairment often goes unidentified and can be confused with other conditions including coordination disorders, learning disabilities, and autism (Chokron & Dutton, 2016; Chokron et al., 2020). It is clear from the findings in this study that children with mild CVI must have clinicians that understand CVI and can diagnose and treat it and have practitioners to support them in their learning environments. Because if they do not, the risk is inadequate or inappropriate interventions that may not work for the child with CVI. Future research in the area of CVI requires us to gather larger sample sizes of participants and seek the perspectives from families, practitioners, and individuals with CVI themselves.

The review of the educational documentation in this study showed that children with CVI are presented with many visual demands in their educational programming, and it is not clear whether or not any other literacy mode besides print media (visual) has been determined appropriate by their evaluations as the information was not readily available or evident in their documents. Future work in this area might investigate how TVIs are qualified to perform LMAs on their students with CVI.

The participants in this study were all middle-aged, white, college-educated females and there were only three of them. These women had a shared experience and were perfect candidates for this research, but they were all very similar. They all lived in the midwestern or southeastern United States within an hour’s drive of the same children’s hospital clinic where their children are patients and attend therapies. Thematic analysis does not encourage generalizations beyond these cases, but each case offers a rich description of the case in order to understand its complexity. The goal of this research is transferability, which clarifies how and in what ways the knowledge and understanding found here can be applied in other contexts, settings, and conditions. I hope that I have revealed their potential application to reach a broader context that can one day inform our practice of teaching students with CVI.

Limitations

While the transferability of this study could be applied to other families with CVI who have also had clinical and educational experiences, these participants were selected by the clinical research coordinator and the lead site investigator at the clinic. They relayed they would choose participants who they thought would want to provide the information requested and be a part of the study. So, these moms might not represent other moms. But, the purpose of the study was for the mothers to present their own experiences, and that goal was achieved.

A study with a larger, more diverse sample size with children who attend public schools would be of interest. There are other programs around the United States that have CVI-specific clinics in larger and more diverse American cities. This study design is limited by the hospital I chose to work with, but another hospital might also be able to work with a researcher to conduct the study on a larger scale. This study represents some of the beginnings of future research in this area and one where understanding the lived experiences of parents of children with CVI and individuals with CVI themselves can inform our knowledge and ability to help.

The mothers in this study all attended outside therapies with their daughters and had the experience at the clinic. They all spoke very highly of the clinic and the staff and learned a lot from them. It would be interesting to compare their experiences to a group that went to a pediatric ophthalmologist at a private practice. Also, the clinical documentation was very comprehensive; it would be interesting to see educational documentation where this information is not provided. This is usually the experience I have at my own job. I have to do the assessments and provide the information.

Another limitation was that I did not have one of the children's evaluations. I could have painted a richer picture if I could also see the clinical information as it was featured in Jenny's evaluation, but her mother did not provide it. Getting the IEP documentation was not difficult for this study as the clinical research coordinator managed the process. If a larger study were to be conducted, it would be a unique challenge to review larger amounts of records and analyze the data. I do think this would be a worthwhile endeavor.

Additionally, a more robust data set would have resulted from interviews with the students' TVIs and general educators who worked with the students. Interviews or data collected from in-depth conversations with them would potentially help to reveal what support is used for these students and the barriers that inhibit growth and the pathways that help them. It could also shed light on the resources they have at their disposal to address CVI on their caseloads. Observations in the classrooms could provide snapshots of the resources that are available to the students and how they use them in the classroom and therapy settings.

Because I am me, I could not help but insert myself into this study. During interviews, I had to stifle all the resources I wanted to share with the mothers and all the ideas I had for their child's instruction. I was able to do it--most of the time. But this is not to say that my own experiences with CVI did not emerge once in a while as I discussed the topic with the participants. I noted my reflections in my research journal to ensure my thoughts and biases did not interfere with the data.

Conclusion

Cerebral visual impairment is a complex disability. While it is a visual impairment, one of the features is an absence of ocular insult. In other words, CVI is an invisible disability. Children like the ones in this study, who suffered brain damage during early developmental periods, are at risk for it. These children fall into the “mild” CVI category of children “who have functionally useful vision and who work at or near the expected academic level for their age group” (Lueck & Dutton, 2015, p. 14).

Research on this level of CVI is not currently available at the practitioner level. Teachers of the visually impaired struggle to provide interventions for these students (Morse, 2018), and they are frequently misdiagnosed with learning disabilities and behavior disorders (Williams et al., 2021).

Through qualitative multiple-case investigation and analysis of participant interviews triangulated with clinical and educational document analysis the following categories and sub-themes emerged; (a) the shifting roles of mothers--mother, advocate, professional; (b) mothers’ experiences within educational systems--navigating educational landscapes, apprehension and possibility; and (c) CVI without a TVI--team CVI awareness, sharing CVI-specific knowledge, and transferring knowledge to team. These themes shed light on the mother’s experiences in the clinical and educational settings and how they were able to provide insight on their child’s CVI to support teams and clinicians. They also showed the transfer of information about CVI, the education team’s responsiveness to the information (from both the mothers and the clinic, separately and together), and the responsibility of implementing the educational plan by individuals who do not have background knowledge in CVI.

The mothers in this study might still be wondering why their child has particular behaviors or falls frequently and has trouble maintaining attention and focus if they had not gone to the pediatric ophthalmology team at this children's hospital. The diagnosis was available to them because of their circumstances and geographic location.

It is my hope that more comprehensive services for children with CVI like the ones at this clinic develop in the future. Already, we are doing work to create more clinical and educational spaces where work like this can be achieved. The implications for the field of blindness and visual impairment are that the population of students we serve is changing, or has already changed, and we need to be ready for it about 20 years ago.

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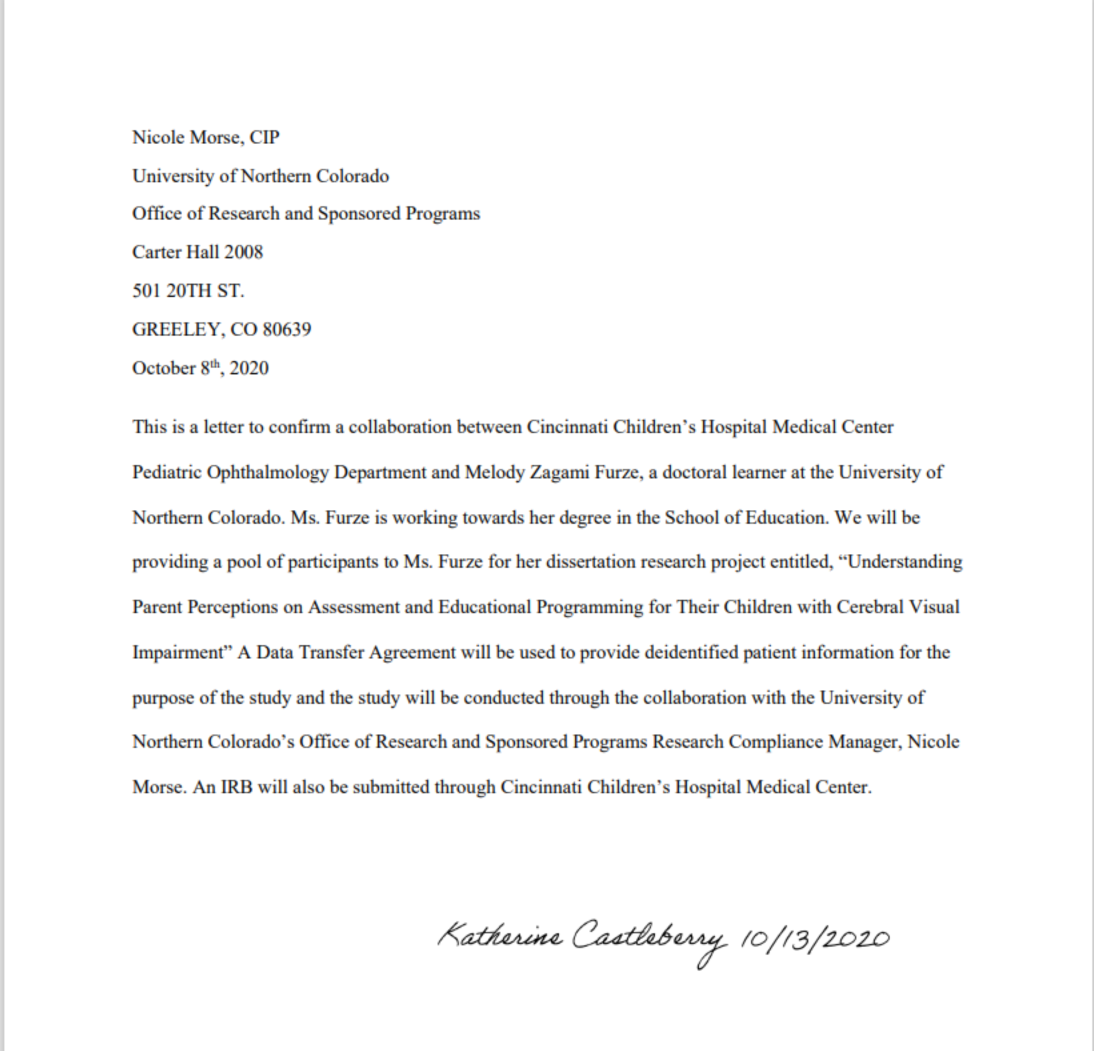
APPENDIX A

COLLABORATION LETTER: CINCINNATI CHILDREN'S HOSPITAL



Nicole Morse, CIP
University of Northern Colorado
Office of Research and Sponsored Programs
Carter Hall 2008
501 20TH ST.
GREELEY, CO 80639
October 8th, 2020

This is a letter to confirm a collaboration between Cincinnati Children's Hospital Medical Center Pediatric Ophthalmology Department and Melody Zagami Furze, a doctoral learner at the University of Northern Colorado. Ms. Furze is working towards her degree in the School of Education. We will be providing a pool of participants to Ms. Furze for her dissertation research project entitled, "Understanding Parent Perceptions on Assessment and Educational Programming for Their Children with Cerebral Visual Impairment" A Data Transfer Agreement will be used to provide deidentified patient information for the purpose of the study and the study will be conducted through the collaboration with the University of Northern Colorado's Office of Research and Sponsored Programs Research Compliance Manager, Nicole Morse. An IRB will also be submitted through Cincinnati Children's Hospital Medical Center.

Katherine Castleberry 10/13/2020

APPENDIX B

DEMOGRAPHIC SURVEY--PARTICIPANTS

Demographic Survey - Participants

(*Collected via phone prior to Interview)*

Thank you for contributing your experiences as a parent/caregiver of a child with CVI to my study. The information collected in this form will provide demographic information about yourself and your child. I will use this when reporting the data and results from the documentation and your interviews. All personal information will be de-identified in the final paper to protect your privacy and confidentiality.

Contact Information:

1. Name:
2. Contact: (number and email)

Child Information

3. Age:
4. Gender:

5.) What grade level is your child currently?

Under 5th grade

6th grade

7th grade

8th grade

9th grade

10th grade

11th grade

12th grade

18 + program

Post-secondary yrs. ___________

Additional Comments:

____

____

6.). Do you have a child with a diagnosis of CVI?

7.) Age when he/she/they obtained CVI diagnosis

8.) How many years has your child received special education services?

9.) Did you child receive early intervention services?

Please list: ____

10.) Have you participated in your child's IEP or 504 plan in the last 5 years?

11.) Is your child currently receiving direct or consultative services from a certified teacher of the visually impaired?

12.) At what age did your child receive a diagnosis of CVI?

13.) Does your child have any other medical conditions?

14.) Did your child attend preschool?

15.) Where does your child spend most of their school day? (check: general education classroom, special education classroom, combination of general education/special education, a specialized school for children with visual impairments?

16.) What are the titles of service providers on your child's IEP team? Check all that apply: (special education teacher, teacher for students with visual impairments, teacher of the deaf/hard of hearing, occupational therapist, physical therapist, speech language pathologist, mental health professional, nurse, type of service providers are on are the roles of people on your roles?

17.) Does your child receive any therapeutic services outside of the school day? If so, please check: (occupational, physical, or mental health therapy)

Parent Information:

18.) Gender
Male
Female
Other
Prefer not to answer

19.) Age (years)
20-30
31-40
41-50
51-60
60+
Prefer not to answer

20.) Ethnicity
African American
Caucasian
Latino/a
Native American/Asian
More than one
Other
Prefer not to answer

21.) Highest Education Level
High school/Associate's
Bachelor's
Master's
Master's +
Doctorate
Alternative Certification
Prefer not to answer

22.) Geographic Area
Urban
Rural
Suburban
Prefer not to answer

** What are the best days for you to virtually meet or talk on the phone to do your interview?
Weekday Evenings

Weekend Morning

Weekend Afternoon

Weekend Evenings

APPENDIX C

LETTER OF APPEAL TO PARTICIPANTS

Date:

Dear Participant (Insert name),

Greetings, I am a teacher of students with visual impairments. I am researching educational programming and outcomes for children with Cerebral/Cortical Visual Impairment (CVI). This letter is to ask for your participation in a research study. I am partnering with the Pediatric Ophthalmology Department at Cincinnati Children's Hospital Medical Center to do this study. The goal of this study is to understand family views of the educational assessments and services provided to their children and how they relate to their CVI diagnosis. I am hoping to talk with you about your experiences with your child's diagnosis, educational meetings, services, and challenges and successes. If you agree to participate, your child's assessments and medical records from the Pediatric Ophthalmology Department at Cincinnati Children's Hospital Medical Center will be reviewed. I will also ask you to share your child's educational documents (IEP/Assessment results) and any vision-related assessments done by their special educators.

Thank you for considering this request to help us better understand family views of children's CVI.

Please contact Melody Furze furz9424@bears.unco.edu / cell (505) 259-7300 with any questions.

Sincerely,

Melody Zagami Furze

Doctoral Student

School of Special Education

University of Northern Colorado

If interested in participating in this study, please click here to complete the survey.

APPENDIX D

PARTICIPANT SAFEGUARDS AND ELECTRONIC CONSENT

Title of research study: Understanding Parent Perceptions on Assessment and Educational Programming for Their Children with Cerebral Visual Impairment

Key Information:

The following is a short summary of this study to help you decide whether to be a participant in it. More detailed information about the study is listed later in this form. This document does not replace the discussion you should have with the research team about this study including having any questions or concerns answered.

If you are 18 years and older: This is a consent form. It explains this research study. If you decide that you want to be in this research study, then you will sign this form to show that you agree to be part of this study. If you sign this form, you will receive a signed copy of it for your records.

Parents/Guardians: You have the option of having your child or teen join this research study. This is a parental permission form. It explains this research study. If you decide that your child can be in this study, you will sign this form to show that you agree. If you sign this form, you will receive a signed copy for your records.

COMBINED Parental Permission/Assent: If you are a parent or legal guardian of a child who may take part in this study, permission from you is required. The assent (agreement) of your child may also be required. When we say "you" in this form, we mean you or your child; "we" means the study doctor and other staff.

Investigators:
Melody Furze, M.ed, University of Northern Colorado
Melissa Rice, OD, Cincinnati Children's Hospital Medical Center

Contact Info:
(505) 259-7300
(513) 636-4751

Funding: Cincinnati Children's Hospital Medical Center Division of Ophthalmology

Reason for the study:

The main reason for this research study is to see if families believe the educational needs of students with CVI are being met with their academic and functional goals and programming. This study will also look at parent experiences supporting their children with CVI and their role as members of their child's educational team.

Procedures:

You will be asked to complete a short survey about yourself and your child as well as their CVI and their experience with education and therapy services. You will also be asked to complete a one hour phone or video conference interview and provide the researchers with more information on your child's CVI educational programming. You will be asked to complete an interview in your preferred format, either by video or phone, to provide the researchers with more information about your experiences with your child's educational programming.

We expect that you will be in this research study until you have completed the phone or video conference interview.

More detailed information about the study procedures can be found under ***“(Detailed Procedures)”***

Risks to Participate:

There is no medical or behavioral intervention as a part of this study. There are no known risks associated with taking part in this research.

Benefits to Participate:

There are no benefits to you from your taking part in this research. However, possible benefits to others include creation and implementation of education programming for students with CVI that better address barriers or pathways to create successful educational outcomes for students with CVI.

Other Options:

Participation in research is completely voluntary. Your decision to participate or not to participate will not affect the care you receive.

Your alternative to participating in this research study is to not participate.

Cost to Participate:

Taking part in this research study may lead to added costs to you. The costs may include message, data, or minute rates that may apply to your phone plan.

Payment:

You will not receive payment for taking part in this study. You (your child) will not be reimbursed for your time while you are in this research study.

Additional Study Information:
The following is more detailed information about this study in addition to the Key Information.

If I have Questions or would like to know about:

■ **Who to talk to…**	■ **You can call …**	■ **At …**
• Emergencies • General study questions	**PI Name** **Melody Furze, M.ed**	Phone: (505) 259-7300

Who to talk to…	**You can call …**	**At …**
• Research-related injuries • Any research concerns or complaints	Melissa Rice, OD	(513) 636- 4751
• Emergencies • General study questions • Research-related injuries • Any research concerns or complaints	**Lead Study Coordinator** Monica Sandoval	Phone: (513)-803-5045
• Your child's rights as a research participant	**Institutional Review Board** This is a group of scientists and community members who make sure research meets legal and ethical standards.	Phone: (513) 636-8039

Detailed Procedures:

As a part of this study you will be asked to:

- Complete a short survey about yourself and your child as well as their CVI and their experience with education and therapy services.
- Send the researchers any special education, Individual Education Programs (IEPs), 504 plans, and any other vision-related test results that are not from Cincinnati Children's Hospital Medical Center Division of Ophthalmology. You are allowed to decide not to give us this additional information. You must send us this additional information in order to participate in this study. If you think you might not want to provide this additional information, you should not chose to take part in this study.
- You may be asked to complete an interview with the investigator in charge of this study. This phone or video conference interview will take about 90 minutes and will be scheduled for a time that is convenient for you. The investigator will ask you questions about your child's CVI and how it relates to any difficulties your child may have. You are allowed to decide not to answer all of the questions. This interview will be audio or video recorded, depending on if the interview is conducted over the phone or by video conferencing, to make sure we accurately document your responses.
- If you cannot complete the whole interview in one session or if there are questions about how you responded to some of the questions asked during the interview, the researcher may contact you again by phone or video conference at your soonest convenience after the first interview session.
- You may be contacted about other research in the future.

Change of Mind/Study Withdrawal:

You can leave the research at any time; it will not be held against you.

If you decide to leave the research, contact the investigator in writing so that the investigator can withdraw you from the study.

If you stop being in the research, data already collected may not be removed from the study database.

Privacy:

Efforts will be made to limit the use and disclosure of your personal information, including research study and medical records, to people who have a need to review this information. We cannot promise complete privacy. Organizations that may inspect and copy your information include the IRB and other representatives of this organization. Study staff and the IRB at the University of Northern Colorado may also inspect and copy this information.

Monitors, auditors, the IRB, and the Food and Drug Administration will be granted direct access to your medical records to conduct and oversee the research. By verbally agreeing to this document, you are authorizing this access. We may publish the results of this research. However, we will keep your name and other identifying information confidential.

AUTHORIZATION FOR USE/DISCLOSURE OF HEALTH INFORMATION FOR RESEARCH

To be in this research study you must also give your permission (or authorization) to use and disclose (or share) your "protected health information" (called PHI for short).

What protected health information will be used and shared during this study?

Cincinnati Children's Hospital Medical Center (Cincinnati Children's) will need to use and share your PHI as part of this study. This PHI will come from:

- Your Cincinnati Children's medical records
- Your research records

The types of information that will be used and shared from these records include:

- Reports and notes from clinical and research observations
- Imaging (like CT scans, MRI scans, x-rays, etc.) studies and reports

Who will share, receive and/or use your protected health information in this study?

- Staff at all the research study sites (including the University of Northern Colorado and Cincinnati Children's)
- Personnel who provide services to you as part of this study
- Other individuals and organizations that need to use your PHI in connection with the research.
- The members of the Cincinnati Children's Institutional Review Board and staff of the Office of Research Compliance and Regulatory Affairs.

How will you know that your PHI is not misused?

People that receive your PHI as part of the research are generally limited in how they can use your PHI. In addition, most people who receive your PHI are also required by federal privacy laws to protect your PHI. However, some people that may receive your PHI may not be required to protect it and may share the information with others without your permission, if permitted by the laws that apply to them.

Can you change your mind?

You may choose to withdraw your permission at any time. A withdrawal of your permission to use and share your PHI would also include a withdrawal from participation in the research study. If you wish to withdraw your permission to use and share PHI you need to notify the study doctor, listed on the first page of this document, in writing. Your request will be effective immediately and no new PHI about you will be used or shared. The only exceptions are (1) any use or sharing of PHI that has already occurred or was in process prior to you withdrawing your permission and (2) any use or sharing that is needed to maintain the integrity of the research.

Will this permission expire?

Your permission will expire at the end of the study.

Will your child's other medical care be impacted?

By signing this document, you / your child agree to participate in this research study and give permission to Cincinnati Children's to use and share you/your child's PHI for the purpose of this research study. If you refuse to sign this document you/your child will not be able to participate in the study. However, you/your child's rights concerning treatment not related to this study, payment for services, enrollment in a health plan or eligibility of benefits will not be affected.

SIGNATURES

The research team has discussed this study with you and answered all of your questions. Like any research, the researchers cannot predict exactly what will happen. Once you have had enough time to consider whether you/your child should participate in this research, you will document your permission by signature below.

You will receive a copy of this signed document for your records.

____
Printed Name of Research Participant

____ _____________
Signature of Research Participant Date
Indicating Consent or Assent

_______________________________________ _____________
Signature of Parent or Legally Authorized Date
Representative*

____
* If signed by a legally authorized representative, a description of such representative’s authority must be provided

____ _____________
Signature of Individual Obtaining Consent Date

APPENDIX E

INTERVIEW PROTOCOL

Interview Protocol

1. What do you know about your child's visual abilities?
2. What is the primary source of this information?
3. Please tell me about your experience during your child's special education meetings.
4. What specific assessments have been reviewed as part of those meetings?
5. What input have you given during those meetings? Specific to CVI or other areas of disability?
6. How has the information from the evaluations at CCMCH has been used in your child's educational plan?
7. How did the evaluations at CCMCH assist you in contributing to your child's special education meeting?
8. In what way has information from your children's CVI specific educational assessments have been used in developing your child's educational plan? If so, what areas of the plan do you recognize that this is the case? Goals/Objectives, Supplementary Aids and Services, Testing accommodations, etc.?
9. How is your child's curriculum or learning program adapted to meet their needs in regard to CVI? How do you know this?
10. Are your child's learning needs (regarding their visual disability) being met? Why or Why not?

11. What areas has your child had success in, in school?

12. What areas has your child had difficulty in, in school?

13. What is the biggest challenge you face in working with your child?

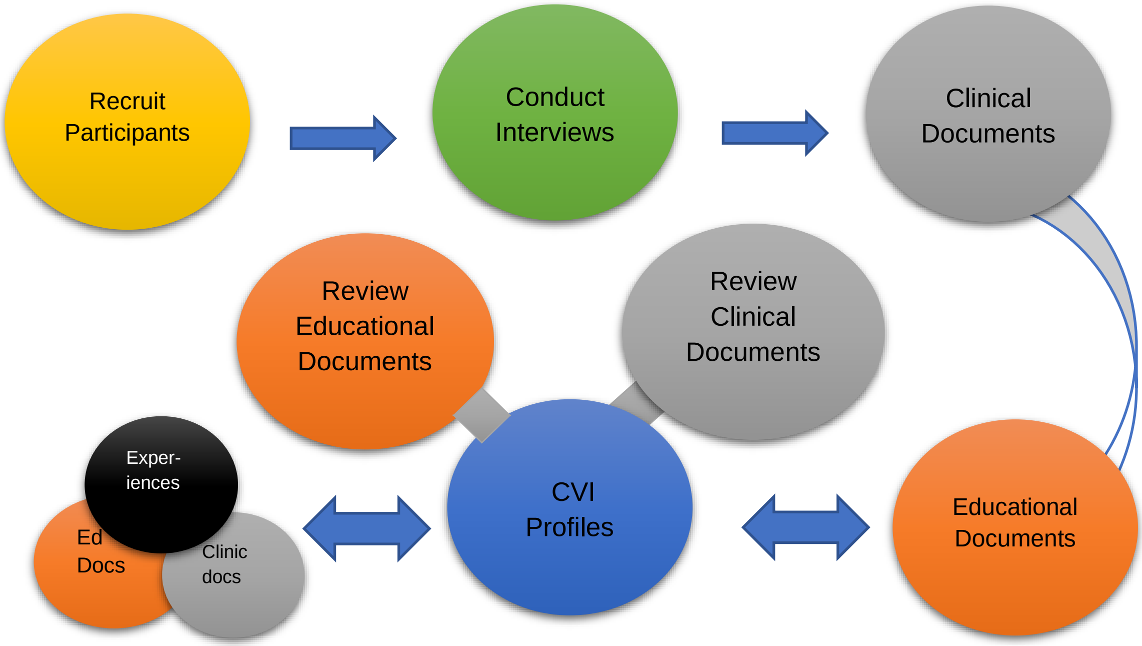
14. What is the biggest joy?

15. Is there anything else about your child’s education that you would like to share with me?

APPENDIX F

DATA COLLECTION FLOWCHART

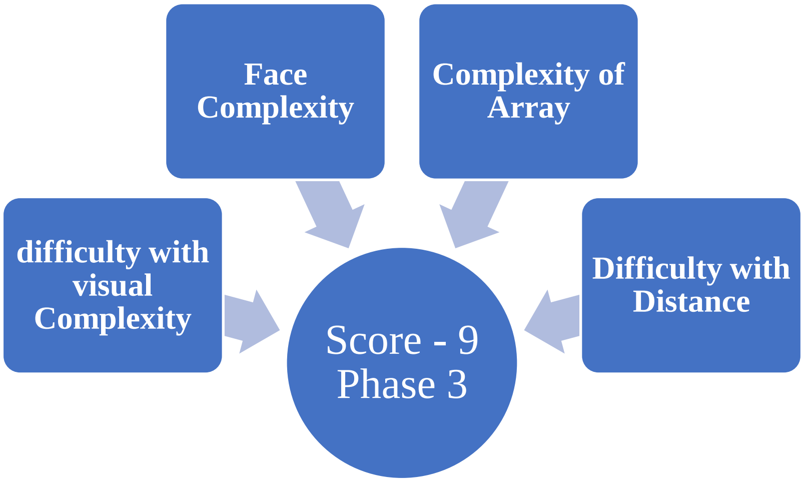
Data Collection Flowchart



APPENDIX G

CEREBRAL VISUAL IMPAIRMENT RANGE ASSESSMENTS

Jenny's Cerebral Visual Impairment Characteristics



Difficulty with Visual Complexity

The assessor reported that Jenny was confused when labeling animal figures with similar visual characteristics and struggled to discriminate between other items. She required demonstration and prompting to put them together.

Complexity of Array

Jenny located objects on a plain blue background, however when the same objects were placed on a visually busy background, she struggled to locate the requested items. She could locate the requested picture on a busy background but required extra time and reminders to find it.

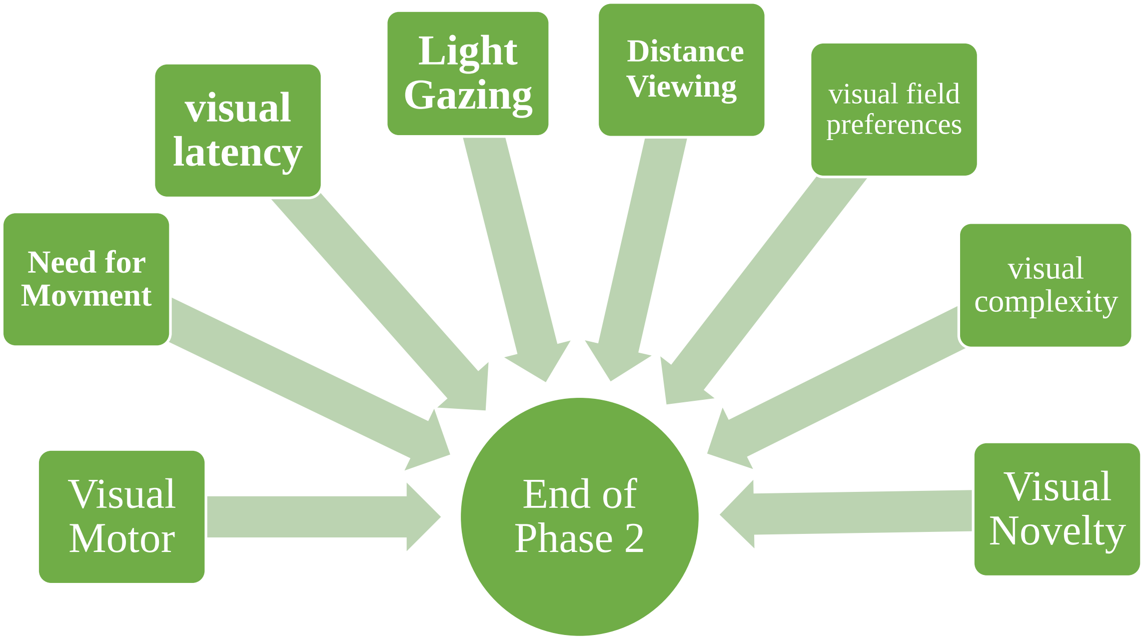
Face Complexity

Jenny demonstrated appropriate eye contact, but her mother reported she often hides during social events.

Difficulty with Distance

Struggled to follow directions to attempt a distance viewing task. She was able to accurately identify familiar pictures from 10 feet away. Parents reported that she takes longer to find items when they are pointed out at a distance. Parents reported she gets very close when reading.

Abby's Cerebral Visual Impairment Characteristics



Need for Movement

Abby was distracted by people moving around her. She moved the piece of fabric when it was too difficult for her to find the beads on it.

Visual Latency

She said, “I don’t know,” as the visual challenges got increasingly difficult

Visual Field Preferences

Prefers to have images propped up when reading books at home. Missed some of the items in her inferior (lower) visual field when finding objects on increasingly complex backgrounds.

Difficulty with Visual Complexity

The more complex the background the more difficulty she had finding visual targets. Even more difficult if they were multi-colored. She wanted to use a tool to block out visual information when looking at more than 5 items. When the visually complex demands of viewing faces are present she appears to look past you or through you. May have brief fixations on faces of familiar people. She also demonstrated difficulty with additional sensory information in a busy hallway and froze frequently and needed additional prompting to complete the tasks.

Difficulty with Visual Novelty

She needs help identifying salient features of more abstract, full, images.

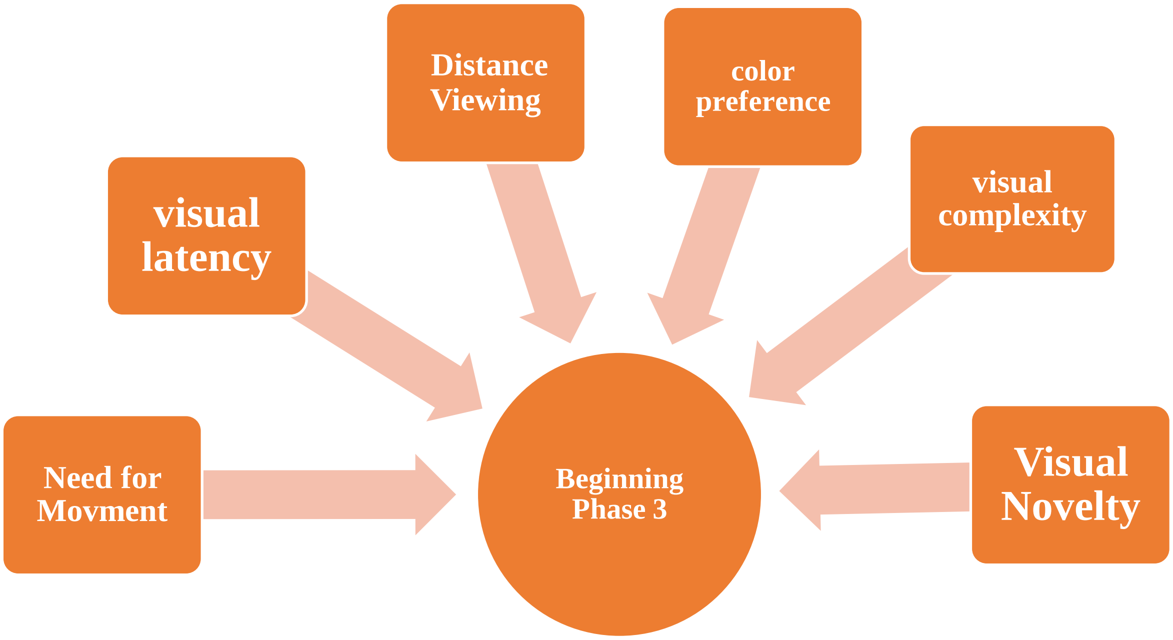
Visual Motor

Abby’s motor impairments affect her ability to perform a visually guided reach and look task. Reaching and looking as a simultaneous action was recorded about 75% of the time and look, look away, reach primarily occurs when materials are highly novel or complex.

Light Gazing

Mother reported she likes to use a spotlight when doing search and find books at home.

Grace's Cerebral Visual Impairment Characteristics



Need for Movement

Distracted by people walking by at a distance of 10 feet away

Visual Latency

Became overwhelmed and stalled when she was unfamiliar with activities

Difficulty with Visual Complexity

Searched and looked at many complex two-dimensional images but had difficulty with black and white images. Had difficulty with visual complexity when asked to find an object in a picture.

Distance Viewing

Fixates on a specific target in a familiar settings. Visual attention on large moving objects at distances up to 20 feet away.

Visual Novelty

New objects or images are recognized or identified based on salient, defining, features. Demonstrates a variety of visual curiosity in most new environments

Visual Motor

Motor impairment minimally affects her ability to perform a task that requires visually guided reach. Look and reach together occurred more than 75% of the time. It rarely occurs when materials are completely novel or highly complex.

APPENDIX H

DATA USE AGREEMENT

THIS DATA USE AGREEMENT ("Agreement") is entered into as of the date of lastsignature (the "Effective Date") by and between Children's Hospital Medical Center, an Ohio non-profit corporation located at 3333 Burnet Avenue, Cincinnati, OH 45229 ("CHMC") andUniversity of Northern Colorado located at 501 20th Street, Campus Box 143, Greeley, CO 80639 ("Recipient") (each a "Party," and collectively, the "Parties").

WITNESSETH

WHEREAS, CHMC and Recipient are collaborating on a research study known as

Understanding Parent Perceptions on Assessment and Educational Programming for Their

Children with Cerebral Visual Impairment, CHMC Protocol/IRB No. 2020-0871 (the "Study")in accordance with the research protocol attached hereto as Exhibit A (the "Protocol");

WHEREAS, the Parties wish to enter into this Agreement so that CHMC may share thedata as further described in the Protocol (the "Data") with Recipient, and Recipient shall use such Data, in a manner that complies with the Health Insurance Portability and AccountabilityAct of 1996, Public Law 104-191 ("HIPAA") and regulations promulgated thereunder by the

U.S. Department of Health and Human Services codified at Title 45 parts 160 through 164 of the United States Code of Federal Regulations, as amended from time to time (the "HIPAA Regulations") and other applicable laws and regulations.

WHEREAS, CHMC is providing the Data to Recipient solely for the Study, and Recipient agrees to use the Data solely for the Study in accordance with the terms and conditions contained in this Agreement.

NOW THEREFORE, for mutual consideration, the sufficiency of which is acknowledged by both Parties, the Parties incorporate the foregoing recitals and agree as follows:

1. Definitions. Terms used, but not otherwise defined, in this Agreement shall have thesame meaning as those terms in the HIPAA Regulations.

2. Permitted Uses and Disclosures. Recipient will use the Data created in the conductof the Study only for the purposes stated herein and will not use the Data for any other purpose.Recipient may use or disclose the Data to perform functions, activities or services limited to research under the Study, only as specified in this Agreement, or as required by law. Recipientwarrants that the use and receipt of the Data will be limited to the individuals authorized for such access by that Party's Institutional Review Board ("IRB") or the equivalent.

3. Data Ownership. CHMC retains ownership of the Data and Recipient shall at all times recognize CHMC as sole owner of the Data without restriction or limitation.

4. Obligations and Activities of Recipient. Recipient represents and warrants that itwill:

(a) not use or further disclose the Data other than as permitted or required by this Agreement or as required by law;

(b) use appropriate safeguards to prevent use or disclosure of the Data other than as provided for by this Agreement;

(c) not use the Data, alone or in combination with other information, to contact any individual who is the subject of the Data provided to Recipient;

(d) make reasonable efforts to limit the use or disclosure of Data to the minimum amount necessary to accomplish the intended purpose of the use or disclosure of the Data; and

(e) ensure that any agent, including a subcontractor, to whom the Recipient provides theData received from CHMC, agrees to the same restrictions and conditions that apply through this Agreement to Recipient with respect to the Data.

(f) maintain the Data in a manner reasonably calculated to preserve the security and confidentiality of the Data; and

(g) report in writing to CHMC any use or disclosure of Data that is not provided for bythis Agreement of which Recipient becomes aware within five (5) business days.

University of Northern Colorado

By: Chris Saxton

5. Term and Termination.

(a) Term. This Agreement will remain in effect so long as Recipient receives, retains,or has access to the Data covered by this Agreement.

(b) Termination by Recipient. Recipient may terminate this Agreement at any time upon ten (10) days written notice to CHMC.

(c) Termination by CHMC. CHMC may terminate this Agreement at any time upon ten (10) days written notice to Recipient.

(d) Termination for Cause. Upon CHMC's knowledge of a pattern or practice that constitutes a material breach or violation of this Agreement by Recipient, CHMC will take,and Recipient will cooperate in taking, reasonable steps to cure the breach and mitigate any reasonably anticipated consequences of such breach. If such steps are unsuccessful, CHMC may, in addition to any other rights CHMC may have under this Agreement or by operation oflaw, immediately terminate this Agreement, discontinue disclosure of Data to Recipient, and report the violation to the Secretary.

(e) Effect of Termination. Upon termination of this Agreement for any reason, Recipient shall return or destroy the Data created or received from CHMC, or created or received by Recipient on behalf of CHMC. This provision shall apply to the Data that is in thepossession of subcontractors or agents of Recipient. Recipient shall retain no copies of the Data. Recipient is responsible for the cost of the return of Data to CHMC. In the event that Recipient determines that returning or destroying the Data is not feasible, Recipient shall

extend the protections of this Agreement to such Data and limit further uses and disclosures ofsuch Data to only those purposes that make the return or destruction not feasible, for so long asRecipient maintains such Data.

(a) Survival. Sections 2 Permitted Uses and Disclosures, 3 Data Ownership, 4 Obligations and Activities of Recipient, 5(e) Effect of Termination, 5(f) Survival, 6 Publication, 7 Audit Rights, 8 Assumption of Liability and 9 Indemnification of this Agreement will survive any termination of this Agreement.

2. Publication. Except as provided under this Agreement, Data may not be shared by Recipient for any purpose with any individual or entity outside of Recipient without the priorwritten consent of CHMC. The Parties acknowledge that the Study is a collaborative effort. The Parties agree to coordinate their respective activities regarding publication prior tosubmission of a paper or abstract for publication. The purpose of this coordination is to ensurethe proper collation and presentation of the Data and to reflect the collaborative nature of the Study. In the event of publication or disclosure of results that is not a joint publication or disclosure, the publishing Party shall grant the other Party the opportunity to review and/or comment on such proposed publication, abstract, or oral presentation. The publishing Party shall grant the non-publishing Party no less than thirty (30) days to review such proposed disclosure. The non-publishing Party may reasonably request in writing that the proposed publication or disclosure be delayed for up to an additional thirty (30) days as necessary for thefiling of a patent application. The non-publishing Party may further request that its confidentialinformation be deleted, but at no time will the publishing Party be required to remove any information relating to the results of the Study, or any other information that is reasonably required by the publishing source to be included in the publication or presentation. The publishing Party agrees that the source of the Data shall be acknowledged in accordance with scientific custom in all published or oral communications concerning the Study.

3. Audit Rights. To allow CHMC to certify its compliance with the HIPAA Regulations, Recipient will permit CHMC, at CHMC's expense and on five (5) days prior notice, to audit Recipient's systems and services, with specific emphasis on Recipient's compliance with the provisions of this Agreement. Such audit, which may be conducted by CHMC's personnel under obligations of confidentiality or by an independent auditing firm, will not unreasonablyinterfere with Recipient's legitimate activities, and will be conducted no more than once per calendar year, unless CHMC has received a request from the Secretary, or unless CHMC has reason to believe that this Agreement has been breached. CHMC will use the information received during an audit solely for the purposes of the Agreement and will otherwise maintainthe confidentiality of such information.

4. Assumption of Liability. Recipient assumes all liability for damages which may arisefrom Recipient's use, storage or disclosure of the Data.

5. Indemnification. Recipient shall indemnify, defend, and hold harmless CHMC and itsofficers, directors, trustees, agents, and employees (collectively, "Indemnitees") from and against any and all losses, expenses, damages, actions, claims, liabilities, or injuries (including,without limitation, all costs and reasonable attorney's fees) that the Indemnitees' may sustain asa result of, or arising out of, (i) breach of this Agreement by Recipient or its agents or subcontractors, including but not limited to any unauthorized use, disclosure, or breach of theData, or (ii) any negligence or wrongful acts or omissions by Recipient or its agents or

subcontractors, including without limitation, failure to perform Recipient's obligations under this Agreement or applicable law. Notwithstanding the foregoing, nothing in this Section 9 shall limit any rights that CHMC may have to additional remedies under the Agreement or under applicable law for any acts or omissions of Recipient or its agents or subcontractors.

6. Miscellaneous.

(a) Warranty. Recipient agrees that the Data provided by CHMC is experimental in nature, and CHMC makes no warranties, expressed or implied, regarding the quality of any product produced under this Agreement.

(b) Governing Law. This Agreement shall be governed by Ohio law, and exclusive jurisdiction of any dispute under this Agreement shall be in the federal or state courts, as applicable, in Hamilton County, Ohio.

(c) Change in Law. The Parties agree to negotiate in good faith to amend this Agreement to comport with changes in federal law that materially alter either or both Parties' obligations under this Agreement; provided, however, that if the Parties are unable to agree to mutually acceptable amendment by the compliance date of the change in applicable law or regulations, either Party may terminate this Agreement as provided in Section 5.

(d) Interpretation. Any ambiguity in this Agreement shall be resolved to permit CHMCto comply with the HIPAA Regulations.

(e) No Third Party Beneficiaries. Nothing in this Agreement will confer upon any person other than the Parties and their respective successors or assigns, any rights, remedies, obligations, or liabilities whatsoever.

(f) Counterparts. This Agreement may be executed in one or more counterparts, each of which will be deemed an original, but all of which together will constitute one and the sameinstrument.

(g) Amendments. This document states the entire agreement between the Parties regarding the Data provided by CHMC to Recipient. Any amendment to this Agreement mustbe in writing and signed by both Parties.

(h) Waiver. No delay or omission on the part of either Party in exercising any right hereunder will operate as a waiver of such right or of any other right under this Agreement. Awaiver on any one occasion will not be construed as a bar to or waiver of any right or remedyon any further occasion. The election of either Party of a particular remedy on default will notbe exclusive of any other remedy, and all rights and remedies of the parties hereto will be cumulative.

(i) Notices. Any notices required or permitted under this Agreement will be in writingand delivered in person or sent by registered or certified mail, return receipt requested, properpostage prepaid, properly addressed to the address of the addressee set forth above or to such other more recent address of the addressee of which the sending Party has received written

7. notice.

8.

9. **IN WITNESS WHEREOF**, the Parties hereto have executed this Agreement effectiveas of the Effective Date.

10.

11.

12. **Children's Hospital Medical Center**

13.

By: Jana Bazzoli

Its: Director, ORSP　　Its: Vice President, CCRF

Date:

Date: 8/30/2021

Reviewed by:

APPENDIX I

STUDENT ACTION PLAN

Student Information:

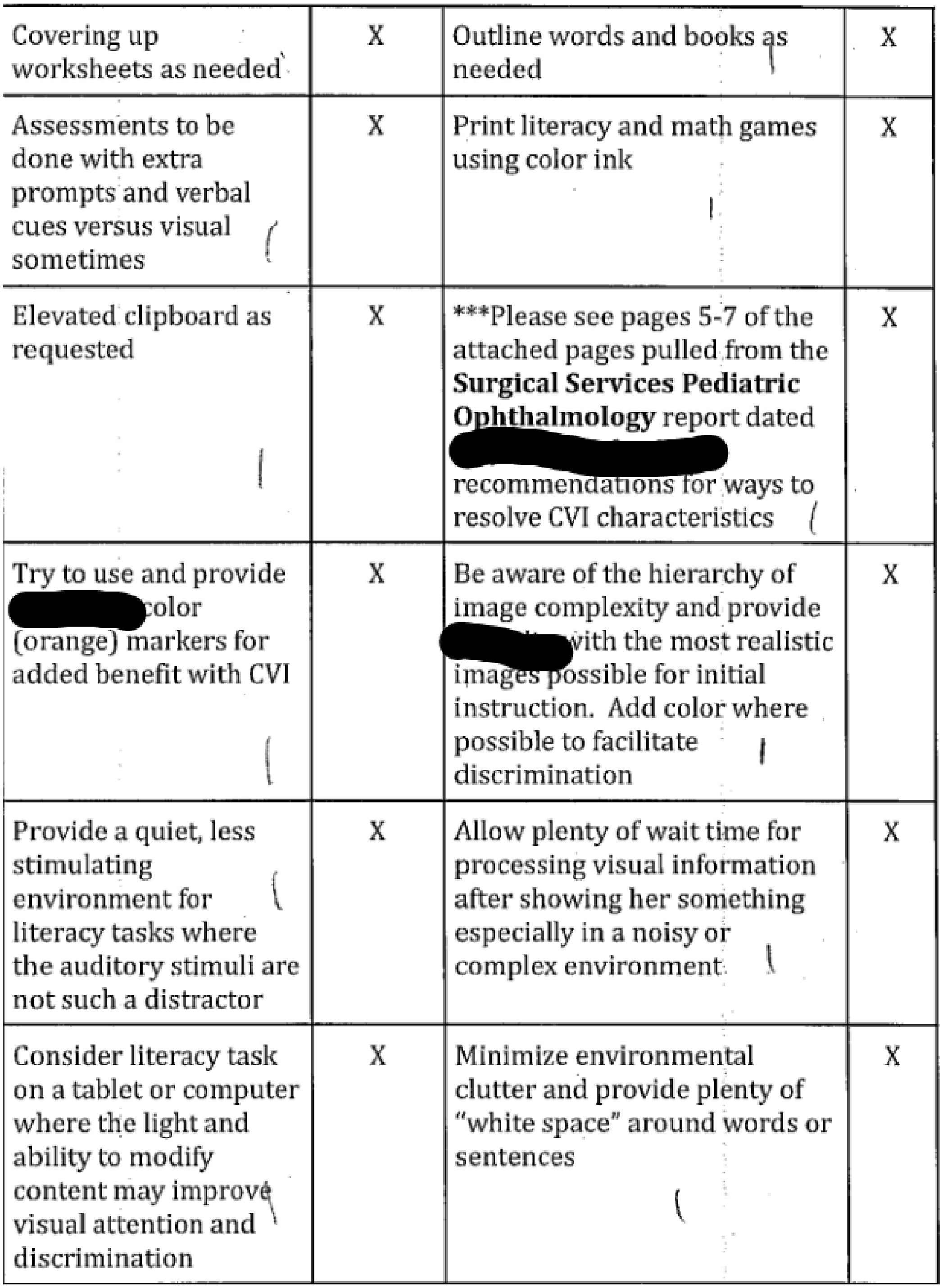
Name:	[redacted]
D.O.B.	[redacted]
Grade:	1st
School Year:	2020-2021 (written in March 2021)

Identified Disability:

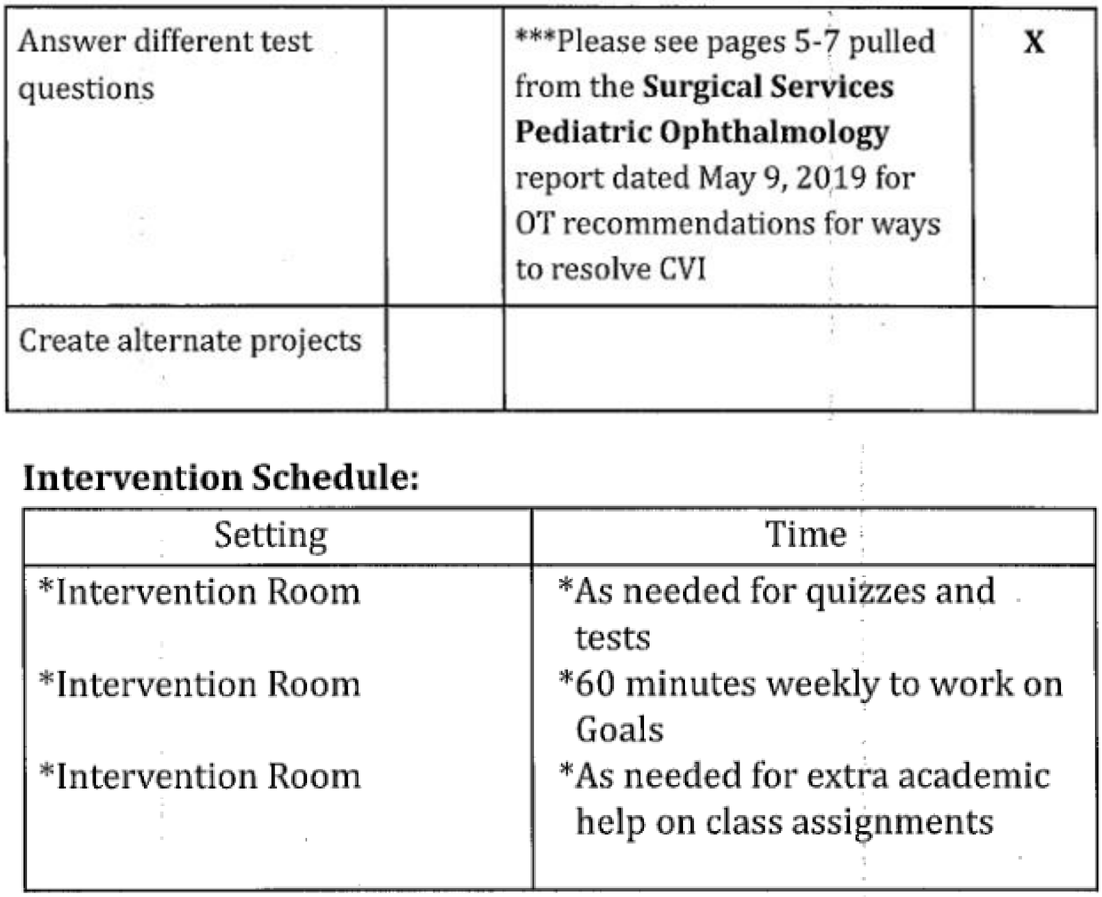
- Multiple Disabilities
  **Other Health Impaired
  **Visual Impairment
- Other Health Impairment
  **Hypoxic Ischemic Encephalopathy
  **Encephalomalacia
  **Polymicrogyria
  **Cerebral Palsy

Goals and Objectives:

- When given a list of 10 CCVE grade level words, [redacted] will blend the sounds and read the words orally with 80% accuracy on ⅘ trials.
- When given a list of 10 CVCE grade level words, [redacted] will blend the sound and read the words orally with 80% accuracy on ⅘ trials.
- When given a piece of paper, [redacted] will write the numbers 1-100 in order with 90% accuracy on ⅘ trials.
- When given 10 (ten) 2 digit written addition problems, Serenity will solve them correctly with 80% accuracy on ⅘ trials.
- When asked to do so, [redacted] will count to 100 orally with 80% accuracy on ⅘ trials.



Covering up worksheets as needed	X	Outline words and books as needed	X
Assessments to be done with extra prompts and verbal cues versus visual sometimes	X	Print literacy and math games using color ink	X
Elevated clipboard as requested	X	***Please see pages 5-7 of the attached pages pulled from the **Surgical Services Pediatric Ophthalmology** report dated [redacted] recommendations for ways to resolve CVI characteristics	X
Try to use and provide [redacted] color (orange) markers for added benefit with CVI	X	Be aware of the hierarchy of image complexity and provide [redacted] with the most realistic images possible for initial instruction. Add color where possible to facilitate discrimination	X
Provide a quiet, less stimulating environment for literacy tasks where the auditory stimuli are not such a distractor	X	Allow plenty of wait time for processing visual information after showing her something especially in a noisy or complex environment	X
Consider literacy task on a tablet or computer where the light and ability to modify content may improve visual attention and discrimination	X	Minimize environmental clutter and provide plenty of "white space" around words or sentences	X



Answer different test questions		***Please see pages 5-7 pulled from the **Surgical Services Pediatric Ophthalmology** report dated May 9, 2019 for OT recommendations for ways to resolve CVI	**X**
Create alternate projects			

Intervention Schedule:

Setting	Time
*Intervention Room	*As needed for quizzes and tests
*Intervention Room	*60 minutes weekly to work on Goals
*Intervention Room	*As needed for extra academic help on class assignments

APPENDIX J

HOSPITAL PROTOCOL APPROVAL

Hospital Protocol Approval

1 V1.0/ 17 Feb 2021 Understanding Parent Perceptions on Assessment and Educational Programming for Their Children with Cerebral Visual Impairment Version 1.0 17 February 2021 Principal Investigator, the University of Northern Colorado: Melody Furze, M.ed Supervising Faculty Member, the University of Northern Colorado: Silvia Correa-Torres, Ed.D Lead Site Investigator: Melissa Rice, OD 2 V1.0/ 17 Feb 2021 1: BACKGROUND AND SUMMARY 1.1 Cerebral Visual Impairment Cerebral Visual Impairment (CVI) is a disorder of the visual processing areas of the brain caused by damage of the visual pathways and visual centers. It also involves the pathways serving visual perception, cognition, and visual guidance of movement and it may coexist with anterior visual pathway anomalies.1 Cerebral Visual Impairment is the principal cause of visual impairment in children in the developed world, with the vision loss ranging from mild visual processing difficulties to total blindness.2 – 4 Cerebral visual impairment is a form of neurological visual impairment. Neurological visual impairment refers to a condition that originates in various areas or networks across the brain and affects the way visual information is processed. When compared to other common causes of childhood visual impairment such as cataracts and retinopathy of prematurity (ROP), which now have more effective treatments, the relative contribution of CVI to childhood visual disability is increasing.4-8 This increase is attributed to advancements in medical technology used to treat preterm and at-risk infants who are surviving at increased rates in both, the developed and developing worlds. 1.2 CVI Assessment and Intervention Children with all forms of CVI require specific, targeted intervention developed through comprehensive assessment and built into their educational programming and goals. The literature on specific interventions based on assessment show improvement in visual function and, in some cases, acuity.1,8-15 Children are more able to adapt and recover from aspects of CVI.15 Prerequisites for these adaptations are visual curiosity, attention, learning, memory, and executive function. However, it has been shown that simply living in the natural environment does not elicit visual improvement and thus,13 the importance of developing a comprehensive profile of children with CVI is of utmost importance. In other words, specific

interventions that are based on a student's precise visual needs and modifications to learning materials and environment are most effective.12 These interventions are vital for improvement and progress and most effective if they are implemented in the child's daily routines and activities.1,9,12-13,16-17 For students with visual impairment, family involvement is crucial to providing a complete, holistic approach to assessment and interventions.18 Furthermore, for students with CVI family input should be the priority as it provides the most optimal approach to learning about the abilities of the child and their comfort levels in certain environments.16 While it is acknowledged that family participation is important and leads to better outcomes for students with visual impairments and other disabilities.18,23-25 The academic literature is scarce on integrating family input into assessment and IEP documentation and programming specifically for students with CVI. Careful integration of assessment results and considerations are important for all students with disabilities, but for children with any type of visual impairment they are especially vital. These students might not be receiving the educational services they require due to coexisting learning and other disabilities, or they might be receiving services for visual impairment, but they have not been assessed for potential disability in other areas.26-27 Evaluation for students with visual disabilities involves more than just typical academic and achievement testing. Students with visual disabilities require assessment for appropriate learning media, necessary accommodations for access to class materials and activities, and instruction in the Expanded Core Curriculum.23 Much of the evaluation, particularly for those students with multiple impairments who have higher risk for CVI, require careful observations in a variety of 3 V1.0/ 17 Feb 2021 environments. Survey interviews and inventories completed by parents, students, and educators are key to developing programming and instruction that leads to educational success.23 It is known that consistent interventions embedded throughout daily routines are the cornerstones of effective instruction for children with CVI.9,16-17 The most effective teaching interventions for this population combine clinical understanding of visual deficits, developmental understanding of the child's abilities, and awareness and practical approaches to assist with missing, overwhelming, or unreliable information from the environment. There is very little literature as to whether student educational documentation such as goals and objectives, provision of supports, and appropriate accommodations are created in this manner. There is also little to no information as to how educational assessments (including functional vision assessments [FVAs] Learning Media Assessments [LMAs] communication, social and behavioral and areas of the Expanded Core Curriculum [ECC] for students with visual impairment and assessments specific to CVI) are incorporated into student goals, adaptations, and information. These assessments joined with family input help educational teams to provide comprehensive services for students with CVI. Parental understanding of CVI has increased in the last 20 years. There are still evidence that special and general educational teams who have students with CVI in their classrooms do not receive information about CVI. Other service providers such as occupational therapists, psychologists, speech-language pathologists, or physical therapists do not get comprehensive information about CVI unless it is explicitly taught to them by a TVI or they seek the information out themselves.19-22 There have been no studies on parent experiences and reflections of the clinical and educational assessments and the processes of IEP programming and implementation for students with CVI. 1.3 Study Objective The goal of the proposed study is to examine if the educational needs of students with CVI, as perceived by their families and set forth by clinical and educational documentation, are represented in their academic and functional goals and programming. This research project will be conducted in a collaboration between the University of Northern Colorado and the Department of Pediatric Ophthalmology at Cincinnati Children’s Hospital Medical Center (CCHMC). The PI at the University of Northern Colorado has chosen CCHMC as a collaborator for this study because of their close work with families of children with this diagnosis in their monthly CVI clinics. CCHMC is unique because of the participant pool at the clinic, the standard of care administered for their patients with CVI, and their conduction of visual functioning and CVI specific assessment. This research will serve to identify how educational services match a student’s CVI profile. This profile is created from the clinical and educational assessments that the team created during the educational planning and implementation process. Research on this topic could shed light on the processes involved in the creation and implementation of education programming for students with CVI. This study will also explore parent perceptions of their experiences advocating and supporting their children with CVI and their role as members of their child's educational team. Since comprehensive assessment and specific programming is crucial for the success of students with CVI, the results of this study could construct a comprehensive picture of the outcomes of clinical and educational assessment and opportunities for collaboration with families of children with CVI. It may also serve to help us better understand the barriers or pathways to create successful educational outcomes for students with CVI. 4 V1.0/ 17 Feb 2021 2: CONSIDERATIONS 2.1 Risks Participation is completely voluntary. The decision to participate or not will not affect any relationship with the research team. Participation in this study will require approximately 90 minutes to complete the interview. There is a potential risk of loss of confidentiality. The information of all participants in this study will be kept as confidential as possible. The personal information from records obtained from CCHMC will be redacted whenever possible while retaining the ability to conduct this research prior to data being transferred to the researcher. All identifiable data that is sent to the PI at the University of Northern Colorado will be sent by Secure Email that includes encryption to minimize the risk of a breach of PHI. All educational records including IEPs and assessments will be de-identified upon receipt, manually if received in hard copy form and labeled with a pseudonym. Control F will be used if received in electronic form. The document will be scanned visually then the identifying information will be replaced with a pseudonym. Every effort will be made to maintain confidentiality and only researchers involved in the study will have access to the data. "Researchers" include the primary researcher, research advisor, peer reviewer, and study staff involved in the study at both the University of Northern Colorado and CCHMC. All audio recordings of interviews and conversations will be transcribed and coded. These files will reside on a password-protected laptop within a password-protected file separated from other files. All audio files will be erased upon transcription completion. Any hard copies of special education documents will be kept in a locked file cabinet in the CCHMC site PI's office or study coordinator's work space. No personal information will be shared at any time. During interviews participants will choose pseudonyms to be used in the results section of the written report. Because this is a small sample size and the focus is the lived experiences of family members in the context of their roles as caregivers and experts, participants will be able to choose their own pseudonyms so that their identity is protected in the study results and future potential publications. The use of pseudonyms is helpful in an approach as it maximizes the researcher's ability to conduct ethical, relational research. The use of self-selected pseudonyms is common in psychology research where lived experiences are to be reported.28 Children's identifying information will not be shared, educational documentation will have names and identifiers such as birth date and school identification numbers removed. The clinic's name will not be published in the dissertation. The purpose of data collection will be explained to the participants during the informed consent process, prior to participation in the study. There is a minimal risk for emotional discomfort associated with answering questions during the interview. There are no other foreseen potential risks, discomforts, or inconveniences as this study involves voluntary completion of the interview. 2.2 Benefits There will not be direct benefit to the subjects. The potential benefit of this project is that at the conclusion, we will have a better understanding of parent perceptions of their experiences advocating and supporting their children with CVI and their role as members of their child's educational team. This could impact the processes involved in the creation and implementation of education programming for students with CVI by helping us better understand the barriers or pathways to create successful educational outcomes for students with CVI. 5 V1.0/ 17 Feb 2021 2.3 Risk Assessment It is the investigator's opinion that the protocol's level of risk falls under DHHS 46.404, which is research not involving greater than minimal risk. 2.4 Reporting of Adverse Events There are no expected adverse events associated with this study. The investigator will abide by CCHMC IRB reporting requirements. 2.5 Study Costs This study will be funded internally through CCHMC Departments of Pediatric Surgery and Ophthalmology. The department of Ophthalmology will be the final dispenser of funds. The subject or his/her insurance provider will be responsible for any costs that are considered standard care. 3: ENROLLMENT 3.1 Eligibility Assessment A child is considered for the study after undergoing a routine eye examination (as part of standard care) where CVI is identified and the child appears to meet the eligibility criteria for enrollment. The study will be discussed with the child's guardian(s). Guardians who express an interest in the study will be given a copy of the informed consent form to read. Informed consent must be obtained from the guardians prior to performing any study-specific procedures that are not part of routine care. Participants will be chosen from a pool of patients that will serve to meet the inclusion criteria for the project. Up to 5 participants, each from independent families, will be enrolled one at a time. 3.2 Inclusion Criteria • Guardians must be 18 years old or older • Guardians must have at least one child diagnosed with CVI who is currently receiving care from the Pediatric Ophthalmology Department CVI Clinic at CCHMC • Guardians must have participated in a minimum of 2 Special Education Meetings • Children must between ages 5-10 years, inclusive • Children must present with “mild” to “moderate” CVI 3.3 Exclusion Criteria • Children must not have any additional disabilities 3.4 Sample Size Up to 5 family members will be recruited initially and enrolled one at a time, but only three will be participating in the study. The additional recruits will serve as backups in case of attrition. 6 V1.0/ 17 Feb 2021 4: STUDY VISITS OUTLINE 4.1 Informed Consent (Day ≤0) Authorized study staff will obtain informed consent from eligible legally authorized guardians prior to initiation of any assessment that is not standard of care. The study will be discussed with the child’s guardian(s). Guardians who express an interest in the study will be given a copy of the informed consent form to read. As the informed consent process will be conducted remotely, a waiver of written documentation of consent is requested. Study staff will provide all participants with a copy of the informed consent form via email or postal mail and will answer all questions prior to documenting verbal informed consent/parental permission in the study record. 4.2 Survey Completion (Day 1) Selected potential participants will answer questions in an online survey in REDCap(see included survey with this IRB submission) to determine the goodness of fit for the study. Information gathered pertains to family member and child demographics such as grade, age, and additional special education services. 4.3 Interview (Day >1) Once participants are selected, a data transfer agreement (DTA) will be used to share identifiable and de-identified patient information including the child's ophthalmological results, exams, and clinic assessments. Participants will also be asked to provide special education documentation including Individualized Education Programs (IEPs), 504 plans, and other visionrelated assessments will be provided in de-identified digital or hard copy formats. Participants will be given a 60

-90 minute interview via phone or virtual meeting platform. Conducted interviews (see included interview questions with this IRB submission) will be semi-structured in nature and feature open-ended questions to learn about the family member's knowledge of their child's visual disability and the educational and functional challenges that accompany it. 5: FOLLOWUP 5.1 Additional Visits Investigators may schedule additional visits at their discretion, to ensure all data is collected according to the interview protocol. Additional phone calls may be scheduled to accommodate the participant's childcare or other scheduling needs. The researcher will provide transcripts of interviews for participants to review and hold another phone conversation if any clarification regarding any of the documentation is required or changes need to be made to the interview transcriptions. 5.2 Management of CVI 7 V1.0/ 17 Feb 2021 The patient's CVI will continue to be monitored and managed by the investigator or her colleagues throughout the duration of this study. No medical or behavioral interventions will take place as a part of the study. 6: MISCELLANEOUS CONSIDERATIONS 6.1 Participant Withdrawals Guardians may withdraw from the study at any time. This is expected to be a very infrequent occurrence due to the short duration of the study. If the guardians indicate that they want to withdraw their child from the study, the investigator personally should attempt to speak with them to determine the reason. If their interest is in transferring the child's care to another eye care provider, every effort should be made to comply with this and at the same time try to keep the child in the study under the new provider's care. 6.2 Discontinuation of Study The study may be discontinued by the investigator prior to the pre-planned completion of enrollment. 6.3 General Considerations The study is being conducted in compliance with the ethical principles that have their origin in the Declaration of Helsinki, with the protocol described herein, and with the standards of Good Clinical Practice. 6.4 Data Transfer Agreement A data transfer agreement will be initiated after initial IRB approval is obtained. This Data Transfer Agreement (DTA) will be initiated by CCHMC for the purpose of the transfer of identifiable data to the PI at the University of Northern Colorado. This data transfer may include a limited data set. No data will be released to the PI at the University of Northern Colorado until this DTA has been approved by both institutions. Additionally, this DTA will cover the transfer of de-identified transcripts to be shared via secure communication from the PI at the University of

Northern Colorado to the CCHMC site investigator. 7: DATA STORAGE AND ANALYSIS 7.1 Analysis Researchers will examine survey data to establish themes. Primary Analyses • To assess how CVI vision/sensory specific needs are reflected or recorded in clinical and educational assessments and IEP documentation • To assess how family understanding and knowledge of CVI contribute to the educational programming or services provided Secondary Analyses • To assess the family's experiences of their child's special education programming and goals for meeting their CVI specific needs 8 V1.0/ 17 Feb 2021 7.2 Data Safety Monitoring Plan The participants in this study are patients routinely seen by the investigator or her colleagues as part of standard clinical care at CCHMC, Division of Pediatric Ophthalmology. Participants will continue to be followed clinically by either the investigator or her colleagues during the course of the research study. No adverse events are anticipated as a part of this study as no medical or behavioral intervention will be administered as a part of the study. 7.3 Source Documents, Case Report Forms Adequate records will be maintained for the study including participant medical records, interview answers, adverse event reports, and information regarding participant discontinuation and reasons for discontinuation. All original source documentation will be stored electronically in the password-protected laptop in a password-protected file apart from other files, on a password-protected CCHMC shared-drive or in a locked filing cabinet located in the investigator's or research coordinator's workspace. All survey data will be collected and housed in a password-protected REDCap database created for this project. At the end of the study, all data and source documents will be de-identified and retained by CCHMC on CCHMC premises and may be used for future undisclosed research. All data transferred to or collected by the PI at the University of Northern Colorado with be transfer to the site investigator at CCHMC prior to the conclusion of the study. At the conclusion of the study any data stored at the University of Northern Colorado will be destroyed. 7.4 Changes to the Protocol The investigator will notify the IRB of any unanticipated problem requiring a change in the protocol to eliminate apparent immediate hazard to a subject per CCHMC Research Policy, R18. Changes that affect the scientific soundness of the study or the rights, safety, or welfare of human subjects will be submitted to the IRB in an amendment prior to implementation. 8: REFERENCES 1- Lueck, A. and Dutton, G., 2015. Vision and the Brain. New York, NY: AFB Press. 2- Hatton, D., Ivy, S. and Boyer, C., 2013. Severe Visual Impairments in Infants and Toddlers in the United States. 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Cerebral/Cortical Visual Impairment: A Need to Reassess Current Definitions of Visual Impairment and Blindness. Seminars in Pediatric Neurology, 31, pp.25-29. 8- Hoyt, C., 2007. Brain injury and the eye. Eye, 21(10), pp.1285-1289. 9- Lam, F., Lovett, F. and Dutton, G., 2010. Cerebral Visual Impairment in Children: A Longitudinal Case Study of Functional Outcomes beyond the Visual Acuities. Journal of Visual Impairment & Blindness, 104(10), pp.625-635. 10- Good, W., Hou, C. and Norcia, A., 2012. Spatial Contrast Sensitivity Vision Loss in Children with Cortical Visual Impairment. Investigative Opthalmology & Visual Science, 53(12), p.7730. 11- Hoyt, C., 2003. Visual function in the brain-damaged child. Eye, 17(3), pp.369-384. 12- Roman-Lantzy, C., 2007. Cortical Visual Impairment. New York: AFB Press. 13- Lueck, A., Dornbusch, H. and Hart, J., 1999. The Effects of Training on a Young Child with Cortical Visual Impairment: An Exploratory Study. 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Impairment. Journal of Visual Impairment & Blindness, 104(10), pp.649- 653. 16- Zihl, J. and Dutton, G., 2015. Cerebral Visual Impairment in Children. 17- Smith, M., Chambers, S., Campbell, A., Pierce, T., McCarthy, T. and Kostewicz, D., 2020. Use of Routine-Based Instruction to Develop Object Perception Skills with Students Who Have Visual Impairments and Severe Intellectual Disabilities: Two Case Studies. Journal of Visual Impairment & Blindness, 114(2), pp.101-113. 18- Goodman, S. and Wittenstein, S., 2003. Collaborative Assessment. New York, N.Y.: AFB Press. 19- Ely, M. and Ostrosky, M., 2018. Applying the Foundational Concepts from Early Intervention to Services Provided to Young Children with Visual Impairments: A Literature Review. Journal of Visual Impairment & Blindness, 112(3), pp.225-238. 10 V1.0/ 17 Feb 2021 20- Jackel, B., Wilson, M. and Hartmann, E., 2010. A Survey of Parents of Children with Cortical or Cerebral Visual Impairment. Journal of Visual Impairment & Blindness, 104(10), pp.613-623. 21- Jackel, B., 2019. A Survey of Parents of Children with Cortical or Cerebral Visual Impairment: 2018 Follow-up. Seminars in Pediatric Neurology, 31, pp.3-4. 22- Mazel, E., Bailin, E., Tietjen, M. and Palmer, P., 2019. A Questionnaire Assessing What Teachers of the Visually Impaired Know About Cortical/Cerebral Vision Impairment. Seminars in Pediatric Neurology, 31, pp.41-47. 23- Lewis, S., & Allman, C.B. 2016. Educational programming. In M.C. Holbrook, T. McCarthy, & C. Kamei-Hannan, eds. Foundations of Education: Volume 1, History and Theory of Teaching Children and Youths with Visual Impairments (3rd ed., pp. 280-321). New York; NY: AFB Press. 24- Stoner, J., Bock, S., Thompson, J., Angell, M., Heyl, B. and Crowley, E., 2005. Welcome to Our World. Focus on Autism and Other Developmental Disabilities, 20(1), pp.39-51. 25- Turnball, A., Turnball, R., Erwin, E. and Soodak, L., 2006. Families, professionals, and exceptionality: positive outcomes through partnerships and trust, 5th edn. Merrill. 26- Fellinger, J., Holzinger, D., Dirmhirn, A., van Dijk, J. and Goldberg, D., 2009. Failure to detect deaf-blindness in a population of people with intellectual disability. Journal of Intellectual Disability Research, 53(10), pp.874-881. 27- van den Broek, E., Janssen, C., van Ramshorst, T. and Deen, L., 2006. Visual impairments in people with severe and profound multiple disabilities: an inventory of visual functioning. Journal of Intellectual Disability Research, 50(6), pp.470-475. 28- Lahman, M.K., Rodriguez, K.L., Moses, L., Griffin, K.M., Mendoza, B.M. and Yacoub, W., 2015. A rose by any other name is still a rose? Problematizing pseudonyms in research. Qualitative Inquiry, 21(5), pp.445-453.

APPENDIX K

UNIVERSITY OF NORTHERN COLORADO INSTITUTIONAL REVIEW BOARD APPROVAL

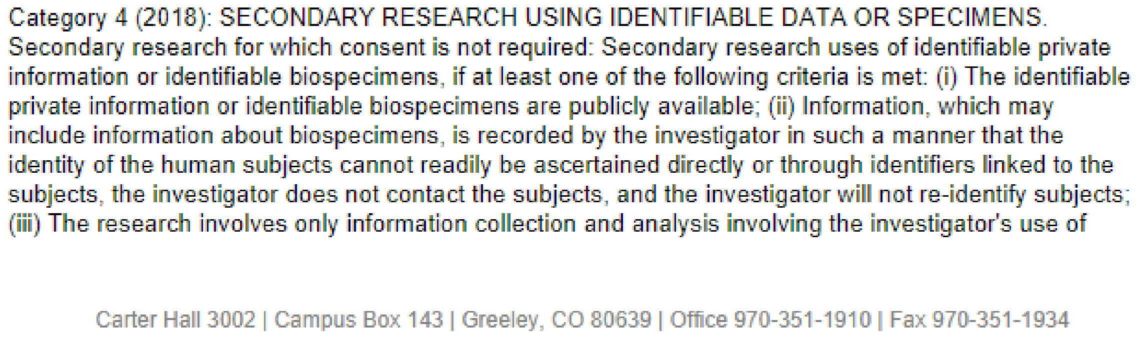
UNIVERSITY OF
NORTHERN COLORADO

Institutional Review Board

Date:	11/23/2020
Principal Investigator:	Melody Furze
Committee Action:	**IRB EXEMPT DETERMINATION – New Protocol**
Action Date:	11/23/2020
Protocol Number:	2009011326
Protocol Title:	Understanding Parent Perceptions on Assessment and Educational Programming for Their Children with Cerebral Visual Impairment
Expiration Date:	

The University of Northern Colorado Institutional Review Board has reviewed your protocol and determined your project to be exempt under 45 CFR 46.104(d)(702) (704) for research involving

Category 2 (2018): EDUCATIONAL TESTS, SURVEYS, INTERVIEWS, OR OBSERVATIONS OF PUBLIC BEHAVIOR. Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met: (i) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained, directly or through identifiers linked to the subjects; (ii) Any disclosure of the human subjects' responses outside the research would not reasonably place the subjects at risk of criminal or civil liability or be damaging to the subjects' financial standing, employability, educational advancement, or reputation; or (iii) The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by 45 CFR 46.111(a)(7).



Category 4 (2018): SECONDARY RESEARCH USING IDENTIFIABLE DATA OR SPECIMENS. Secondary research for which consent is not required: Secondary research uses of identifiable private information or identifiable biospecimens, if at least one of the following criteria is met: (i) The identifiable private information or identifiable biospecimens are publicly available; (ii) Information, which may include information about biospecimens, is recorded by the investigator in such a manner that the identity of the human subjects cannot readily be ascertained directly or through identifiers linked to the subjects, the investigator does not contact the subjects, and the investigator will not re-identify subjects; (iii) The research involves only information collection and analysis involving the investigator's use of

UNIVERSITY OF
NORTHERN COLORADO
Institutional Review Board

identifiable health information when that use is regulated under 45 CFR parts 160 and 164, subparts A and E, for the purposes of "health care operations" or "research" as those terms are defined at 45 CFR 164.501 or for "public health activities and purposes" as described under 45 CFR 164.512(b); or (iv) The research is conducted by, or on behalf of, a Federal department or agency using government-generated or government-collected information obtained for nonresearch activities, if the research generates identifiable private information that is or will be maintained on information technology that is subject to and in compliance with section 208(b) of the E-Government Act of 2002, 44 U.S.C. 3501 note, if all of the identifiable private information collected, used, or generated as part of the activity will be maintained in systems of records subject to the Privacy Act of 1974, 5 U.S.C. 552a, and, if applicable, the information used in the research was collected subject to the Paperwork Reduction Act of 1995, 44 U.S.C. 3501 et seq.

You may begin conducting your research as outlined in your protocol. Your study does not require further review from the IRB, unless changes need to be made to your approved protocol.

As the Principal Investigator (PI), you are still responsible for contacting the UNC IRB office if and when:

- You wish to deviate from the described protocol and would like to formally submit a modification request. Prior IRB approval must be obtained before any changes can be implemented (except to eliminate an immediate hazard to research participants).
- You make changes to the research personnel working on this study (add or drop research staff on this protocol).
- At the end of the study or before you leave The University of Northern Colorado and are no longer a student or employee, to request your protocol be closed. *You cannot continue to reference UNC on any documents (including the informed consent form) or conduct the study under the auspices of UNC if you are no longer a student/employee of this university.
- You have received or have been made aware of any complaints, problems, or adverse events that are related or possibly related to participation in the research.

If you have any questions, please contact the Research Compliance Manager, Nicole Morse, at 970-351-1910 or via e-mail at nicole.morse@unco.edu. Additional information concerning the requirements for the protection of human subjects may be found at the Office of Human Research Protection website - http://hhs.gov/ohrp/ and https://www.unco.edu/research/research-integrity-and-compliance/institutional-review-board/.

Sincerely,

UNIVERSITY OF
NORTHERN COLORADO
Institutional Review Board

Nicole Morse
Research Compliance Manager

University of Northern Colorado: FWA00000784

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