12-2023

# Resiliency in Families of Children With Low Vision

Deborah Lynn Mendoza
*University of Northern Colorado*

## Recommended Citation

Mendoza, Deborah Lynn, "Resiliency in Families of Children With Low Vision" (2023). *Dissertations*. 1039.
https://digscholarship.unco.edu/dissertations/1039

UNIVERSITY OF NORTHERN COLORADO

Greeley, Colorado

The Graduate School

# RESILIENCY IN FAMILIES OF CHILDREN WITH LOW VISION

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

Deborah Lynn Mendoza

College of Educational and Behavioral Sciences
School of Special Education

December 2023

This Dissertation by: Deborah Lynn Mendoza

Entitled: *Resiliency in Families of Children with Low Vision*

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

Accepted by the Doctoral Committee

__________________________________________________
Silvia M. Correa-Torres, Ed.D., Research Advisor

__________________________________________________
Amy Graefe, Ph.D., Committee Member

__________________________________________________
Tracy Gershwin, Ph.D., BCBA-D, Committee Member

__________________________________________________
Jill L. Bezyak, Ph.D., CRC, Licensed Psychologist, Faculty Representative

Date of Dissertation Defense _________________________________________

Accepted by the Graduate School

__________________________________________________________
Jeri-Anne Lyons, Ph.D.
Dean of the Graduate School
Associate Vice President for Research

# ABSTRACT

Mendoza, Deborah Lynn. *Resiliency in Families of Children with Low Vision.* Published Doctor of Education dissertation, University of Northern Colorado, 2023.

Resiliency is comprised of a complex interplay of risk and protective factors that change and develop over time. In the past, research focused on characteristics that allowed individuals to remain untouched by negative events around them; however, over time, this has morphed into investigating not only the characteristics individuals possess but those present within families as well. Families of children who have either a congenital or an acquired disability could face a unique set of risk factors over time that might require different protective factors to ensure they emerged from their adversity positively changed. As professionals, we have a responsibility to assist families in strengthening their protective factors, increasing the likelihood they will develop stronger resilience.

There was little research on resilience within families of children with visual impairments. The purpose of this study was to look at the experiences of families of children with low vision to gain a better understanding of their exposure to risk factors as well as the protective factors they found most beneficial. The following research questions guided this study:

Q1 What role do risk factors play in the experience of families of children with low vision?

Q2 What protective factors do families of children with low vision perceive to be most beneficial?

Q3 What are the challenges that families of children with visual impairments experience and how have they overcome them?

Ten participants who demonstrated consistently high resiliency were nominated by their teachers of the visually impaired for this study. They were asked to complete an initial survey consisting of basic demographic information as well as the Walsh Family Resiliency questionnaire. Those who scored with a 4 or higher and indicated interest in continuing were asked to complete two interviews as well as a short journaling activity. Interviews and journal entries were coded for common themes in the areas of risk and protective factors and how they interacted with each other. Results found five common risk factors in answer to research question one: (a) unsupportive professionals, (b) trust, (c) finding a place, (d) societal perceptions, and (e) uncertainty. Common protective factors to answer research question two were organized into three groups based on Walsh's family resiliency theory: (a) belief systems (positive outlook, acceptance of visual impairment, locus of control, and religion); (b) organizational processes (advocacy and information gathering, outside support, supportive professionals, and technology); and (c) communication processes (goal setting, changing relationships, communication, self-care, and problem solving.

The implications for practice included ensuring that professionals are providing parents with positive professional interactions along with making parents true partners in the process for their child. Professionals provided invaluable support for parents in information gathering at a level that met their needs and ensuring that parents are connected to the resources they require. The results of this study provided a clearer picture of the pattern of resiliency within these families of children with low vision. While every family responded differently based on their unique makeup and backgrounds, understanding these participants provided a starting point for what to look for in other families of children with low vision to better support them.

*Keywords*: resiliency, disability, visual impairment, low vision, vision loss, Walsh Family Resiliency Theory

# TABLE OF CONTENTS

# LIST OF TABLES

Table

# LIST OF FIGURES

Figure

# ABBREVIATIONS

| | |
|---|---|
| IDEA | Individuals with Disabilities Education Act |
| IEP | Individualized Education Plan |
| IRB | Institutional Review Board |
| OSEP | Office of Special Education Programs |
| TVI | Teacher of the Visually Impaired |
| VI | Visual Impairment |

# CHAPTER I

## INTRODUCTION TO THE STUDY AND PERSONAL REFLECTION

Helen Keller once said: “Character cannot be developed in ease and quiet. Only through experience of trial and suffering can the soul be strengthened, vision cleared, ambition inspired, and success achieved” (Good Reads, 2023, n.p.) I found this to be true throughout my life. I experienced the most growth and change through those events that pushed me out of my comfort zone and forced me to reevaluate what was important to me as well as the direction of my life rather than those who allowed the status quo to continue. I entered the world of special education as an occupational therapist to show others that even when faced with what appeared to be an insurmountable problem, there was always a way to creatively conquer it. When presented with the opportunity to become a teacher of the visually impaired (TVI), I jumped at the chance to continue that philosophy in a slightly different realm. One of the most rewarding experiences as a TVI is the ability to watch families and children face what appears to be overwhelming obstacles and come out victorious on the other side. As a TVI, I had the opportunity to work closely with families from Pre-K to transition age, some of whom had children who are congenitally blind, those born with a visual impairment, and others who recently acquired their visual impairment. I have worked across settings providing services in the home, within in the school, and out in the community as an Orientation and Mobility Specialist.

I have seen that a diagnosis of visual impairment has the potential to provide an impetus for change for both the person receiving the diagnosis as well as their families. The trajectory of their path could take many different directions based on a complex interaction of factors that vary for each individual or family. Watching how various families responded to the adversity they faced drove me to seek answers on how to provide support to both students and their families to maximize the potential of the child.

Within the students I worked with, often two types of families emerged. On one side, families advocated for their children to be fully included and complete all the same activities as their peers. They seemed to accept their child’s diagnosis of visual impairment, embrace it, and seek answers on how to mitigate the impact it has on their child and their family as a whole. They acknowledged the differences a visual impairment brought but refused to allow that to define the entirety of who their child is. Throughout the process, they worked well with the school staff, not always agreeing, but always seeking to problem-solv together and move forward in a more positive direction. It was not that they did not experience feelings of fear for their child’s ability to integrate safely into a sighted world, they simply chose to face those fears head on and problem-solv past them.

The children of these families seemed to be more likely to excel academically and reach their full potential. They became involved in more extra-curricular activities and developed stronger, more lasting connections with their peers. Overall, they demonstrated higher levels of self-confidence and self-efficacy. The epitome of this for one specific student on my caseload was when as a high school senior completing her transition paperwork, she never once mentioned her visual impairment as something that would stand in her way or prevent her from achieving her future goals. Even though she was a braille reader, she had so fully integrated her visual impairment into who she was and embraced the adaptations she needed to use so completely she no longer saw them as an issue or an obstacle.

On the other side were families who saw their child’s visual impairment as a burden to be born. They often struggled to accept their child for who they were no matter how successful they were able to be and constantly and vocally sought a cure for what was “wrong” with them. As a result, they often wanted their children to remain dependent to protect them from the negative perceptions of society. They allowed the fear they had for their child to take over and were unable to move past it to see the potential. Partnerships with school staff were much more difficult to develop and they often saw things as an “us versus them” situation.

The children of these families were often more likely to develop and demonstrate learned helplessness. They displayed much more fear of the world and were unwilling to take the risks necessary to learn new skills. Rather than developing good peer relationships, they were more bound to adults. Overall, they demonstrated decreased self-confidence and self-efficacy. Following graduation, they were much more likely to live at home and be un or under employed.

From my experience, in all the years I have been working with students with VI, I noticed that families and children reacted in different ways to the diagnosis of visual impairment they received. As a result, the children had a different outcome in their ability to function within the classroom setting and ultimately within the world outside of school. This has been true even when the support provided from the school was similar and the children all had similar visual prognoses. What then precipitated the very different responses demonstrated? This question continually plagued me as I served kids. Why was there such a large difference in how families and individuals responded regardless of age of onset or severity of diagnosis, and how could I, a professional who is supposed to prepare children for the world outside of school, better support them on that course? This led me down the pathway of looking closer at mental health support, grieving within families, knowledge of disability, and overall resiliency.

# Background on the Problem

## Visual Impairment

The Individuals with Disabilities Education Act (IDEA, 2004) defined visual impairment as “an impairment in vision that, even with correction, adversely affects a child’s educational performance. The term includes both partial sight and blindness” (IDEA, 2004, n.p.). According to the Centers for Disease Control and Prevention (n.d.), visual impairment including blindness is a low-incidence disability with less than 3% of all children ages 18 and under in the United States diagnosed with a visual loss that cannot be corrected by glasses. Data from the Office of Special Education Programs (U.S. Department of Education, 2021) indicated the percentage of students served on an individualized education plan (IEP) under a visual impairment label was less than 0.05%. While these data might not encompass all students with visual impairments as it did not include those students who have visual impairments who are served under a different label such as multiple impairment on their IEP, it served to demonstrate the overall low-incidence rates. Lower incidence limits the availability of support from other parents and children who are experiencing a similar disability as some families have to travel long distances before finding another family who has a child with the same disability (Lupon et al., 2018). When coupled with societal views and perspectives that living with blindness is devastating, families of children with visual impairments have the potential to experience increased stress (Ulster & Antle, 2005). Past research indicated the potential for familial stress to be greater for families of children with low vision than families of children who are blind (Bambara et al., 2009; Lupon et al., 2018; Ulster & Antle, 2005). There was no conclusive evidence of why this was the case; however, it postulated that the uncertainty of what to expect from their child’s vision and therefore uncertainty around their child’s ability levels played a role in the increased stress (Troster, 2001). The ambiguity of a low vision diagnosis may play a part as well. The child does not totally fit into the sighted world; however, at the same time, they are not blind either (Tuttle & Tuttle, 2004).

Visual impairment influences all areas of an individual's life including social, academic, and leisure activities (Lupon et al., 2018). This led to the necessity of changing every facet of the family system with a redefinition of roles and identities (Bambara et al., 2009). Parents often experienced uncertainty around their child's future, doubts about their capacity to meet their child's needs, and worries about the ability to find the resources necessary to best support their child (Leyser et al., 1996). Anxiety around the lack of societal acceptance for their child created another area of concern (Lupon et al., 2018).

For some families, when they received a diagnosis of visual impairment, whether it was congenital or adventitious, grief might be triggered as they are experiencing a loss of what they expected would be true for their child (Tuttle & Tuttle, 2004). Families might experience a continual need to readjust and might move forward and backward within the stages of grief with every milestone as their child did not achieve it in the same way as did other children (Ulster & Antle, 2005). The need for readjustment was magnified when a child was adventitiously blind or had a progressive condition (Ulster & Antle, 2005). The risk factors presented with a visual impairment could be compounded when increased parental stress, poverty, or excessive grief were present.

## Problem Statement

Little research addressed resiliency in families with children who had visual impairments. The risk factors present in having a child with a visual impairment were well documented (Bambara et al., 2009; Lupon et al., 2018; Ulster & Antle, 2005; Zegeye, 2019); however, very few resources were available where protective factors provided the greatest benefit for these families. Children's first teachers are their families and resiliency developed in childhood could provide a lifelong buffer against stress (Khanlou & Wray, 2014). Parenting style directly influences a child's well-being and resilience (Armstrong et al., 2005). With strong parenting, even when there are increased outside stressors, children could demonstrate positive outcomes, and risks for maladjustment were greatly decreased (Mackay, 2003). The level of caregiver resilience/family resilience is one of the strongest indicators of child success and quality of life (Widyawati et al., 2021). Therefore, it is imperative that as professionals we find ways to better support families to increase long-term outcomes for the children we serve.

## Purpose of Study

The purpose of this study was to look at the experiences of families of children with low vision to gain a better understanding of their exposure to risk factors as well as the protective factors they found most beneficial. Participants were drawn from families of children who met criteria to have an IEP in the area of visual impairment for low vision services. For this study, the continuum of low vision covered children who met the initial definition of visual impairment (acuity of no better than 20/70 in the better eye, a visual field of 20 degrees or less, or a condition of the visual system which cannot be corrected) to those who are dual readers (children who read in both print and braille). The child must have had an educational impact and a need for specialized instruction in the area of vision. Results from a resiliency questionnaire, two interviews, and journal entries provided the data necessary to complete my phenomenological study. The focus of the study was on the following research questions.

## Research Questions

Q1 What role do risk factors play in the experience of families of children with low vision?

Q2 What protective factors do families of children with low vision perceive to be most beneficial?

Q What are the challenges that families of children with visual impairments experience and how have they overcome them?

## Methods

I conducted a qualitative study utilizing a phenomenological approach to capture the essence of families' experiences without placing judgment upon them. Participants in this study were families of children with low vision who received educational services for visual impairment. Participants were nominated by their TVI. Families were asked to complete an initial survey including demographic information as well as the Walsh Family Resiliency Questionnaire. Those families who demonstrated a higher level of resilience on the questionnaire and were willing to continue to be part of the study were asked to complete the interviews and journal entries. Interviews focused on looking at the different risk and protective factors they felt were in play for their family. Following their first interview, they were asked to complete short journaling prompts. A second interview that focused on gathering more in-depth information on previously noted themes was then conducted.

All data collected through the survey, interviews, and journals were analyzed utilizing open axial and selective coding. Data were organized into common themes that addressed the stated research questions. Throughout the process, I kept detailed field notes to ensure I was recognizing my bias and employing bracketing. To ensure trustworthiness, member checks, triangulation, and peer reviewing were employed. A more detailed discussion of my methods is found in Chapter III.

## Definition of Terms

**Resiliency.** To develop the definition of resiliency used in this study, I reviewed the varied definitions present within the literature and compiled them into a working definition. For the purpose of this study, resiliency is defined as a dynamic process in which families utilize their strengths and resources to withstand and rebound from a crisis or adversity to move forward stronger.

**Visual Impairment.** The IDEA (2004) defined visual impairment as “an impairment in vision, that even with correction, adversely affects a child’s educational performance” (n.p.). The definition of visual impairment used for this study was the presence of one or more of the following criteria:

- An acuity of no better than 20/70 corrected vision in the better eye (what someone with 20/20 vision sees at 70 feet, this individual needs to be within 20 feet to see)
- A visual field restriction of 20 degrees or less (a decrease in a child’s ability to see input in their peripheral which approaches tunnel vision)
- A physical condition of the visual system that cannot be medically corrected. This could encompass a variety of different visual conditions including but not limited to cortical visual impairment (CVI) and progressive visual conditions where the child might currently have more usable vision but with a prognosis of more vision loss.

To participate in this study, a family’s child must have had an education impact from their visual impairment and be receiving services from a Teacher of the Visually Impaired. Families of children with visual diagnosis such as convergence disorder, strabismus, or amblyopia were not included in the scope of this study. Families of children with vision in only one eye were included if the vision in their remaining eye was impacted enough to fit the above criteria. If the vision in their remaining eye did not meet these criteria, they were not included within the study.

**Low Vision.** For this study, low vision was defined as an individual who has impaired vision that cannot be corrected with corrective lens or surgery and yet provides them enough vision to use for educational purposes such as print reading utilizing magnification devices. Low vision could encompass many varying diagnoses, acuities, and functional vision levels. For this study, the continuum of low vision covered children who met the initial definition of visual impairment to those who were dual readers. As soon as a student was a primary braille reader, they no longer qualified as low vision under this study.

**Dual Readers.** Those students who read in both print and braille. One media might be dominant over the other but they used both throughout their day. Students might become dual readers because their diagnosis had the possibility of progression, they had already lost enough vision to make print reading ineffective full time, or to combat visual fatigue.

**Parents.** For the purpose of this study, parents were defined as any parent, guardian, or caregiver who had primary custody of a child with a visual impairment. Primary custody was important to ensure their level of resilience was the one that was most impactful for their child. I used families, parents, and participants interchangeably.

## Conclusion

Family resiliency plays an integral part in how children develop their own resiliency and how they are able to move out into the world (Armstrong et al., 2005; Khanlou & Wray, 2014; Mackay, 2003; Widyawati et al., 2021). A child’s diagnosis of visual impairment could introduce a higher level of adversity into the life of a family as it influences all facets of life. This is compounded by low-incidence visual impairment as well as societal perceptions of visual impairment.  Few resources are available documenting the protective factors most beneficial after a diagnosis of visual impairment. The next chapter reviews the literature on various definitions of resiliency and how resiliency research has developed over the years. Risk and protective factors are defined and discussed in relation to families of children with disabilities.

# CHAPTER II

# REVIEW OF LITERATURE

Resiliency is comprised of a complex interplay of risk and protective factors that change and develop over time. Initially, research was focused on characteristics that allowed individuals to remain untouched by the negative events around them; however, over time, this morphed into investigating not only the characteristics individuals possess but those present within families as well. Families of children who have either a congenital or an acquired disability could face a unique set of risk factors over time that might require different protective factors to ensure they emerged from their adversity positively changed. To better understand how to assess resiliency, we must first look at how the study of it began and has changed.

## Definition of Resiliency

Resiliency has been an area of interest for researchers for decades and over time, the focus has grown and changed to encompass not only individuals but the systems surrounding them as well. The definition of the term resiliency differs across literature, research studies, and scholars with no one agreed upon definition of the term. The original definition of resilience came from the world of math and science and denoted the ability of a substance to bounce back to its original form (Fletcher & Sarkar, 2013). According to Merriam-Webster (2021), resiliency is “an ability to recover from or adjust to adversity or change” (n.p.). The operative definition has morphed over time to incorporate different components based on the focus of the study or the theoretical understandings of the moment (Fletcher & Sarkar, 2013). Within the realm of social sciences, resiliency was initially seen as a personality trait—something an individual was born with that allowed them to bounce back from abusive or destructive situations (Walsh, 1996). Researchers slowly began to add influences from outside of the individual as well as those that came from within as time went on (Fletcher & Sarkar, 2013).

When looking at individuals, resiliency is seen as the “human potential to emerge from a shattering experience scarred yet strengthened” (Walsh, 1996, p. 264) or “an active process providing rebound from adversity more strengthened, leading to endurance and growth in response to crisis” (Bayrakli & Kaner, 2012, p. 936). Often, resilient individuals are those in possession of “the ability to thrive amid adversity” (Jessup et al., 2019, p. 420). When the focus shifts to families, researchers are looking at “characteristics, dimensions, and properties which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations” (Greeff & Nolting, 2013, p. 397). Resiliency does not consist of a black-and-white process but rather “the capacity of a dynamic system to adapt successfully to disturbances that threaten its function, viability, or development” (Masten & Monn, 2015, p. 6).

Although each description varied slightly, there were two consistent themes throughout every definition of overall resiliency: (a) adversity and (b) positive adaptation to the adversity faced (Armstrong et al., 2005; Fletcher & Sarkar, 2013). Adversity took the form of either an acute event that very quickly changed a family’s situation or smaller daily stressors that built up over time (Fletcher & Sarkar, 2013; Walsh, 2003, 2016a). Generally, the cause of adversity is viewed as rooted in negative events; however, at times, positive events such as a wedding or birth of a baby might be catalysts as well (Fletcher & Sarkar, 2013). The level of adversity present in a situation varied from individual to individual or family-to-family based upon their perception of the event (Greeff & Van Der Walt, 2010). Each event took into account not only what was currently happening but what had happened in the past, and projections around how certain events could affect the future (Walsh, 2003). Walsh (1996) indicated, “Resilience is forged through adversity not despite it” (p. 271), meaning that without difficult situations, individuals and families are not placed in a position that facilitates growth and change.

The definition of positive adaptation varies when addressing family resiliency versus individual resiliency. Positive outcomes for individuals could look like meeting appropriate milestones (Fletcher & Sarkar, 2013), demonstrating appropriate behaviors (Masten & Monn, 2015), or conforming to the expectations of the system they functioned within (Masten & Monn, 2015). For families, resiliency presents as the ability to care for individual members, positively interact with the outside world, and provide economic support for all family members (Masten & Monn, 2015; Peer & Hillman, 2014). What denotes positive adaptation varies based on the severity of the adversity present for a family. In very severe cases, such as instances of prolonged abuse, the lack of extreme dysfunction within the family denotes adaptation even if there are not obvious signs of other positive outcomes (Fletcher & Sarkar, 2013; Masten & Monn, 2015). Strategies that work for a family in one situation might be less functional in another as their circumstances change (Fletcher & Sarkar, 2013; Khanlou & Wray, 2014; Walsh, 1996). For example, in infancy or early childhood, a mother being overprotective and constantly present for their child could be adaptive; however, that same behavior once the child is an adolescent would hamper their growth (Southwick et al., 2014). It is important to note that positive adaptation could look very different in different cultures (Fletcher & Sarkar, 2013; Porcelli et al., 2014; Walsh, 1996). As professionals, we must be careful not to place our own cultural expectations on families when appraising their level of adaptation and resilience. The concept of a “normal” White middle-class family with a stay-at-home mother, father who works, and happy children cannot be projected onto every culture or every family, and families themselves should be encouraged to not hold themselves up to that ideal (Walsh, 2002).

Adversity and positive adaptation are continually present for all of us, providing multiple opportunities to develop resilience. Many experts agreed that resiliency is a process that happens over time rather than a single event; it exists on more of a continuum through which families move back and forth (Greeff & Nolting, 2013; Khanlou & Wray, 2014; Migerode et al., 2012; Walsh, 2016a). Risks and protective factors change over time as a family's situation changes, and their usefulness varies based on the current situation (Fletcher & Sarkar, 2013). For example, a family that shows great resiliency when their child initially loses vision might not be as resilient when that child turns 16 and is unable to drive. The sheer volume of factors that go together to influence resilience makes it inevitable that the process would change over time (Fletcher & Sarkar, 2013). There is no one correct pathway to resilience as it will look different for every family and every time a new stressor appears (Masten & Monn, 2015). For the purpose of this study, resiliency is defined as a dynamic process in which families utilize their strengths and resources to withstand and rebound from a crisis or adversity to move forward stronger. To better understand the concept of resiliency, we must look at the history of research related to it.

## History of Resiliency Research

Early resilience research focused on resilience as a characteristic possessed by certain individuals (Fletcher & Sarkar, 2013; Masten & Monn, 2015; Walsh, 1996). As the definition of resiliency has changed, so has the focus of study, which has now grown to center more on a combination of internal and external factors. Prior to the 1970s and 1980s, resiliency researchers commonly focused on a deficit-based risk approach and perspective (Fletcher & Sarkar, 2013; Porcelli et al., 2014). Researchers looked at children in homes where parents had drug or alcohol addiction or were incarcerated and studied their ability to cope with the situation and move forward in either a positive or a negative way (Anthony & Cohler, 1987; Cohler, 1987). They slowly began to realize that while there were definite dysfunctions such as drug and alcohol abuse, domestic violence, and poverty, many individuals were able to raise above their circumstances. Interest then shifted to determining what characteristics individuals possessed that allowed them to thrive in difficult situations (Hadfield & Unger, 2018; Richardson, 2002; Walsh, 1996). The thought patterns a child had developed, their social skills, personality, and cognitive level were just some of the pieces studied (Khanlou & Wray, 2014). Prevention and strength building became the emphasis of early research rather than simply psychopathology (Southwick et al., 2014).

Resiliency was first seen through a nature perspective—individuals were either born with the characteristics or not and the characteristics came from within the individual rather than from the environment (Fleming & Ledogar, 2008; Walsh, 1996). *The Invulnerable Child*, a compilation of multiple early resiliency studies, showed repeated references to innate characteristics present within children and adults who allowed them to thrive where others failed (Anthony & Cohler, 1987). According to Cohler (1987), successful children demonstrated increased sensory-neural integration, reflective cognitive styles, higher intelligence, and mastery over their own thinking and lives when placed in adverse situations. Invulnerable individuals were characterized as robust infants who inherently possessed a wide range of aptitudes that increased as they grew older (Anthony, 1987). Inherited traits such as high intelligence, well-developed physical skills, and confidence in their ability to overcome created their capacity for resilience (Peck, 1987). The represented authors did not totally discount the presence of external factors in an individual's resiliency, though they emphasized that the makeup of the person's innate characteristics was most important. As time went by, researchers began to shift focus more towards the factors that came from outside of the individual, and a broader lens incorporating both nature and nurture was adapted (Fleming & Ledogar, 2008). They slowly started to move from looking at individual traits to addressing process or relational resilience (Walsh, 1996). With that shift, researchers began to look outside of individuals to those systems that surrounded them.

Initial resiliency researchers delineated families as the source of dysfunction, which precluded them from being protective factors for individuals and limited research into their possible positive or protective characteristics (Walsh, 2016a). Adults such as teachers or social workers were seen as positive influences for a child but family members were not (Walsh, 2002). Then Werner and Smith (2001) conducted a longitudinal study, which indicated that extended family, rather than just community connections, could be protective, changing the emphasis of research. As families became more of the focus of study, initial research mirrored that of individual resilience and focused more on stress, adversity, and crisis (Masten, 2018). Some factors of individual resiliency continued to be important in looking at family resiliency as the ability of individual members, especially parents, positively or negatively impacted overall family resilience (Mackay, 2003; Masten & Monn, 2015). However, researchers now focused on how an individual’s characteristics influenced the entirety of the family unit, rather than just their impact on individual members, and how those traits helped the family to thrive or not thrive (Greeff & Van Der Walt, 2010).

Slowly the focus began to change toward relational resilience, looking at patterns in communication, problem-solving, and use of resources instead of focusing on individual traits (Walsh, 1996). As a result, researchers such as McCubbin and McCubbin (1988) began to look at families in a more positive light; families began to be seen as challenged rather than damaged and as possible sources of strength (Hadfield & Unger, 2018; Walsh, 1996). The focus of McCubbin and McCubbin's work was on military families and how they were able to adjust to adversity. They looked at stressors such as long deployments, frequent moves, and injury or death of a family member (Lavee et al., 1985). Walsh (2016a) focused on families in Chicago who had experienced bereavement, job loss, divorce, chronic illness, or disability among other things. While the populations they studied varied greatly in the types of stressors present, the researchers concluded that different characteristics within families allowed them to move forward in a positive direction from adversity (Lavee et al., 1985; Walsh, 2016a). McCubbin and McCubbin (1988) found some of the most prominent characteristics were strong family traditions and routines, celebrations, and pride in the family. Walsh (2003) postulated that the family's core beliefs, positive outlook, and flexibility provided some of the strongest protective factors. Both researchers indicated the factors that positively influenced families varied greatly based on their ethnicity and across time and situations (McCubbin & McCubbin, 1988; Walsh, 2003). A family's journey to resiliency is a pathway that changes over time as new members join or different stressors appear for members within the family as an individual's stress often influences the entire family unit (Masten & Monn, 2015). Any pathway to resiliency must match a family's values and goals to be effective (McConnell & Savage, 2015).

## Walsh Family Resiliency Theory

The Walsh (2002) family resiliency theory takes into account past research on both individual traits that lead to resiliency, those who helped determine family resiliency, and compiled them together into a single framework that helps to define how families were able to move forward positively. This theory represents a shift away from the medical model and psychoanalysis where the focus was on deficits to a place where the cause does not matter as much as the resolution and building capacity was valued (Walsh, 2002). The base of the theory is the premise that major changes affect an entire family unit, rather than just individual members, and the success of the unit as a whole as well as that of individual members remains dependent upon collective resiliency (Walsh, 2016a).

Dr. Froma Walsh (2002) pulled information from her work with families in Chicago to develop her family resiliency theory. She drew on pieces from past theories and ideas to build the base. Walsh grounded her theory in the family systems theory and incorporated pieces of the bio-psycho-social systems orientation and the stress diathesis model (Walsh, 2002). The family systems theory states that the family is a complex social system wherein the interactions of the individual members influence each other's behavior (Broderick, 1993). Due to the interconnectedness of the family, it could be viewed as one entity rather than simply individual members (Broderick, 1993). The bio-psycho-social system's orientation posits that when looking at a medical condition or situation, the psychological and social/cultural factors are equally important as the biological factors; therefore, the psychological factors must be treated as well as the physical ones (Biopsychosocial model, n.d.). The diathesis-stress model further explains that while there is a genetic or biological root for mental or physical disorders, they require a stressful life situation to be triggered (American Psychological Association, n.d.).

Walsh (2016a) took the findings of other researchers as well as her own, considered them through the lens of past theories and models, and organized them into nine different transactional processes grouped into the three domains defined here:

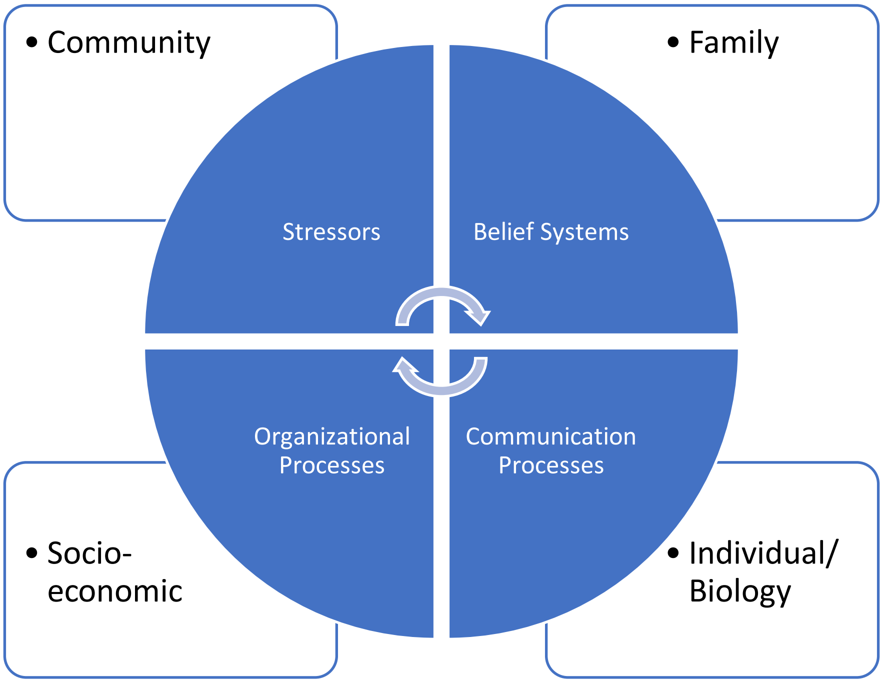
1. Belief systems (making meaning out of adversity, positive outlook, and transcendence and spirituality),

2. Organizational processes (flexibility, connectedness, and mobilizing social and economic resources), and
3. Communication processes (clarity, open emotional sharing, and collaborative problem solving).

Figure 1 provides a visual organization of how the different components of the Walsh family resiliency theory interact with each other as well as being influenced by different environmental components.

**Figure 1**

*Walsh's Family Resiliency Theory*



Walsh's (2016a) family resiliency theory provided a comprehensive summary of the different protective factors that could work together to create resiliency within families. Looking closer at each area allowed me to build an understanding of how each area worked together to support families of children with visual impairments. Throughout this study, the Walsh (2002) family resiliency theory guided how I approached families, chose interview questions and journal prompts, as well as how I organized the protective factor data to report on the results.

## Cultural Diversity

It is important to note that positive adaptation could look very different in different cultures (Fletcher & Sarkar, 2013; Porcelli et al., 2014; Walsh, 1996). As professionals, we must be careful not to place our own cultural expectations on families when appraising their level of adaptation and resilience. Walsh (2002) worked hard within her theory to allow for all types of families and emphasized the idea that families should not be held to the ideal of a traditional White middle-class family with a stay-at-home mother, father who works, and happy children. This emphasis on diversity allowed me to incorporate families from all cultural backgrounds within this study.

Within resilience studies, Western ideals of resilience were dominant; however, they did not fit for every culture and it was up to the researcher to evaluate each situation and determine if the correct ideals were being applied (Ungar et al., 2007). Gathering qualitative data allows researchers to ascertain participants' perceptions on the questions asked and their reasoning behind the responses given. In this way, they are given an opportunity to explain their cultural lens (Ungar, 2006; Ungar et al., 2007). Collectivist cultures as a whole tend to place greater value on interpersonal connections and relationship harmony than do individualist cultures (Guo & Spina, 2019). Differences between collectivist cultures versus individualist cultures lead to differences in their responses to adverse situations (Ungar et al., 2007). If an individual does not view a situation as adverse, then they would not demonstrate increased resiliency within that situation over time as without adversity resilience does not develop (Hickey et al., 2021).

# Contributors to Resilience

Every family possesses both risk factors and protective factors, which could directly or indirectly influence a family as they navigate through stressful events (Mackay, 2003). Risk factors are environmental or personality traits such as poverty, disability, or decreased communication or coping skills, which increase negative outcomes. When too many risk factors are present or the family deems they do not have the capacity to deal with the risk factors present, then decreased resiliency results (Peer & Hillman, 2014). Protective factors are environmental or personality traits such as strong interpersonal ties, optimism, or flexibility, which increase positive outcomes. When the right combination of protective factors exists, families demonstrate increased resilience. Attaining a greater understanding of both risk factors and protective factors produces a stronger understanding of resilience.

## Risk Factors

The bulk of the research completed on resilience within families of children with disabilities involved autism or developmental disabilities as the prevalent disability with few addressing children with visual impairments. Risk factors leading to potentially decreased resilience exist for all families and vary based upon their current situation. Potentially stressful events trigger each member in the family in unique ways and they respond differently based on how successfully they moved through similar events in the past (Walsh, 2003). Children within a family often take their cues on how to respond from their parents (Masten & Monn, 2015). Maladjustment occurs when harmony cannot be restored and the demands exceed the family’s capacity (Greeff & Nolting, 2013). Compounding risk factors create a domino effect necessitating changing adaptation as stressors become chronic rather than acute (Walsh, 2003).

Although risk factors look different for every family, some tend to be impactful across families. While study results focused extensively on the protective factors that were the most beneficial for families, some common themes in risk factors emerged as well. The following section provides a compilation of highlighted risk factors from studies of families with various disabilities.

### *Child's Disability*

When a child is either born with a disability or acquires one over time, the need to adapt begins immediately and the impact on a family has the potential to be catastrophic. The more severe the disability or the more negative behaviors a child demonstrates, the higher the negative impact on the family (Bekhet et al., 2012; Halstead et al., 2018; McConnell et al., 2014). The need to cope begins with the original diagnosis as the family must immediately begin the process of adjustment (Heiman, 2002). Challenges to a family's acceptance of disability occur repeatedly as different milestones are missed, necessitating readjustment (Muir & Strnadova, 2014). Parents often spend extensive amounts of time seeking out resources for their child, coordinating appointments, and ensuring their child's needs are met appropriately, leading to increased stress (McConnell & Savage, 2015; Muir & Strnadova, 2014). Difficulty in finding childcare, constant medical appointments, and increased personal care needs for the child make working difficult, contributing to overall lowered socioeconomic status (McConnell et al., 2014).

Along with the presence of a disability comes an increased burden on parents to become the expert for their child. They feel pressure to gain professional-level knowledge of not only their child's disability but the school system, and what they have a legal right to receive from it (Sanderson, 2023). Many parents feel they are put in a position where they are obligated to seek out and find the necessary services for their child as well as continuing to monitor professionals to ensure those services are carried out appropriately (Muir & Strnadova, 2014). Both parents and professionals are often ill-prepared to collaborate on how to bring together the knowledge parents have with the knowledge the school team brings, increasing tension (MacLeod et al., 2017). This could lead to contentious meetings where parents feel unheard and put in a position where it feels more like an us versus them situation (MacLeod et al., 2017; Sanderson, 2023). This tension creates an environment where it becomes difficult for families to build trust in the system as well as the professionals who work with their children daily (MacLeod et al., 2017; Sanderson, 2023).

For families who have children with a disability, protective factors become even more crucial. The ability to adjust to disability has the capacity to change based not only on the severity of the disability but also the prevalence of the disability within the community and the ability of the family to find community support for themselves and their child. As noted in Chapter I, visual impairment provides its own unique challenges to resiliency within a family.

### ***Societal Perceptions***

Families do not exist in a vacuum. There is a triad among the child with a disability, their family, and the society they live within (Heiman, 2002). The interplay among those three factors frequently leads to increased stress for families. There is often a negative social stigma associated with disability, making it difficult for families to find necessary social and financial resources (McConnell et al., 2014). Society often views having a disability as something to be pitied or a tragedy (Lupon et al., 2018; McConnell & Savage, 2015). Individuals with disabilities are seen as incapable of developing meaningful relationships and unable to contribute meaningfully to society (Zegeye, 2019). Families often feel the need to limit their time in social situations or avoid them altogether so their child's behavior does not affect the event (Muir &

Strnadova, 2014). Reactions from others while completing common daily activities such as shopping has the capacity to stretch parents beyond their limits (Bitsika et al., 2013). Negative stigmas exist not only within society as a whole but also within extended families and parents themselves.

### *Parental Stress*

Parental stress with disability can come in many different forms, all of which potentially lead to a decreased ability to care appropriately for their children, increased parental anxiety and depression, and an erosion of the quality of all family relationships (Peer & Hillman, 2014). Mackay (2003) found that families who had a single parent without support from extended family tended to have increased maladaptive behavior and stress. This was especially true if there was a socioeconomic impact and/or the reason for having a single parent was traumatic for the remaining parent (Mackay, 2003). There was an equally negative impact when teen parenting was involved as there tended to be decreased parenting skills, decreased parental education levels, and increased parental depression (Mackay, 2003).

Marital stress becomes prevalent with the presence of disability as well. When autism is present, the likelihood of divorce increases by 10% (McConnell et al., 2014). Decreased personal time for parents could lead to negative mental health and a withdrawal of one parent from the other causing divorce (Greeff & Van Der Walt, 2010). As parents' burden of care for their child increases, their marital satisfaction often decreases, leading to a decrease in their ability to cope with stress and care appropriately for their child, creating a vicious cycle (Bekhet et al., 2012).

### ***Parental Mental Health***

Increased feelings of depression and anxiety are prevalent within families of children with disabilities (Bitsika et al., 2013; Cramm & Nieboer, 2011; Halstead et al., 2018; McConnell & Savage, 2015; McConnell et al., 2014; Peer & Hillman, 2014). Often when parents have a child with a disability, they struggle to believe they can have a “normal” life, leading to feelings of increased anxiety and depression (Bitsika et al., 2013). Parents, especially mothers, would neglect their own mental or physical health needs to care for their child or the wellbeing of the family (Cramm & Nieboer, 2011). Mothers of children with disabilities could be two to three times more likely to develop depression or anxiety than mothers of children without disabilities (McConnell & Savage, 2015; McConnell et al., 2014). Around 40% of mothers whose children have autism or developmental delays expressed concerns with depression and anxiety (Bitsika et al., 2013; Halstead et al., 2018).

### ***Community Resources and Connections***

Community resources and connections to support families of children with disabilities can be challenging to find (Muir & Strnadova, 2014). Even finding basic childcare or extracurricular activities for a child with a disability become major hurdles (McConnell & Savage, 2015; McConnell et al., 2014). Care providers or instructors without knowledge of disability and how to accommodate for it contribute to increased difficulty in locating services (Jessup et al., 2019). Decreased availability of resources and quality of services requires families to spend disproportionate amounts of time seeking and coordinating services (McConnell & Savage, 2015; Muir & Strnadova, 2014). Connections with friends or other community resources families had prior to welcoming children potentially drop off due to lack of time and balancing care for their child (Cramm & Nieboer, 2011; Peer & Hillman, 2014). When a disability has a low level of incidence, such as visual impairment, families often struggle to find others to connect with who are experiencing similar things, leading to increased isolation (Lupon et al., 2018).

### ***Poverty***

Poverty increases stress on parents (Mackay, 2003; McConnell et al., 2014), decreases nutrition levels for all family members, and decreases the parent's social capital (networks and resources available to a parent to enable them to move forward effectively; Mackay, 2003). Disability within the family could decrease socioeconomic status by limiting the ability of adults to work due to either their own disability or the need to care for another family member (McConnell & Savage, 2015). The overall cost of providing needed services, medical attention, and required devices increases the financial burden for families (Bambara et al., 2009; McConnell et al., 2014; Muir & Strnadova, 2014). The stress felt by children when poverty is present is proportionate to the stress on the adults in the home as they tend to take their cues from their parents (Masten & Monn, 2015).

### ***Grief***

The notion that grief is present in families of children with disabilities has become somewhat controversial. While many researchers listed grief as a contributing risk factor for families to develop decreased resilience (Bambara et al., 2009; Heiman, 2002; Tuttle & Tuttle, 2004; Ulster & Antle, 2005), there is a growing feeling that ascribing feelings of grief to families places them at a disadvantage and sets them up for negative interactions with school personnel (Allred, 2015). The medical model of disability provides the base for grief models and helps to reinforce the idea that having a child with a disability is a tragedy that must be overcome (Allred, 2015). Bonanno (2004) cautioned that not every family or individual might experience grief to the same extent or in the same way as is expected by society. He emphasized that this did not indicate pathology but rather a difference in processing and resilience.

When grief is present, it presents a unique stressor for families. When describing what the grief cycle for families of children with visual impairment may look like, Tuttle and Tuttle (2004) defined seven phases of grief:

1. Trauma, physical or social (initial triggering event)
2. Shock and denial (unbelief that the event has happened, inability to feel)
3. Mourning and withdrawal (no one can understand)
4. Succumbing and depression (too much to bear, too sad to move on)
5. Reassessment and reaffirmation (life is still worth living)
6. Coping and mobilization (changing to meet new demands)
7. Self-acceptance and self-esteem (liking the new reality).

Grief is not a linear process to be moved through and accomplished; rather, it is a cycle with individuals moving in and out of different phases as different events occur (Tuttle & Tuttle, 2004; Ulster & Antle, 2005). Different phases of grief induce either increased or decreased resiliency. Those outside of the family cannot make assumptions about how an individual or family should grieve or if a certain situation is grief-inducing (Allred, 2015). Often, children and parents move through grief at a different pace, creating incongruity within the family (Ulster & Antle, 2005). Grief, like all risk factors, is present for some families and not for others.

## Protective Factors

Protective factors are those environmental or personality traits that increase positive outcomes for families or individuals. For this study, positive outcomes equated with resilience and denoted things such as the ability to care for individual members, positively interact with the outside world, and provide economic support for all family members (Masten & Monn, 2015; Peer & Hillman, 2014). The introduction of new risk factors into a family system cannot be controlled; therefore, protective factors should be strengthened to balance out the risk factors and increase the possibility of growth from adversity (Bekhet et al., 2012). Most of the research into family resiliency was conducted using families who had children with autism, intellectual disabilities, physical disabilities, or developmental disabilities; however, the initial research into families with children who had visual impairments indicated many of the same protective factors such as support systems, cohesion within the family, and active problem solving still applied.

Comparing the studies completed in other disability areas demonstrated a reliance on survey results to determine family's levels of resilience. Though varying scales were used throughout the studies, the main areas of focus were resiliency, coping styles, anxiety and depression levels, social support, family cohesion, problem solving, and overall family satisfaction (Bayrakli & Kaner, 2012; Greeff & Nolting, 2013; Greeff & Van Der Walt, 2010; Greeff et al., 2012; Halstead et al., 2018; McConnell et al., 2014). Only a few studies relied on survey results paired with a single qualitative question for families (Greeff & Nolting, 2013; Greeff & Van Der Walt, 2010; Greeff et al., 2012). Most past disability-specific studies focused on mothers when looking at overall family resilience (McConnell et al., 2014). Only one longitudinal study addressed resiliency over time that was conducted with families of children who had disabilities as well as behavior problems (McConnell et al., 2014). The following sections reflect a compilation of the results of research completed with families of children in disability categories other than vision.

### *Belief Systems*

**Attitude.** The family's attitude toward the stressors in their lives greatly impacts their level of resilience. When a family has an optimistic outlook, they expect positive outcomes for all members of the family, they focus more on the accomplishments of individual members no matter the size, and focus more on strengths than limitations (Peer & Hillman, 2014). Optimism allows families to actively pursue viable solutions to their problems, look beyond the adversities present in their lives, and focus on making the best of a difficult situation (Greeff & Van Der Walt, 2010). They are able to maximize their potential by taking what they have been given and making the best of their options (Walsh, 2003). Resilient families look at a tough situation and believe they will be in the 10% that beats the odds (Walsh, 2003). Overall, optimism leads to decreased negative outcomes and increased coping (Bekhet et al., 2012).

Acceptance of their situation remains an essential piece for families. This can be an ever-evolving process that involves changing a family's perspective of disabilities including how they think and feel about it as well as their ability to find peace with it (Bekhet et al., 2012). A conscious decision must be made to move forward with their lives as a family (De Klerk & Greeff, 2011). One route to this is through passive appraisal, an acceptance of the fact that their situation will not change, and their child is who they are (Greeff & Nolting, 2013; Greeff & Van Der Walt, 2010). More rapid acceptance leads to better overall adjustment; however, the process occurs over varying amounts of time for each family and/or individual and some families are never able to accept a child's diagnosis (De Klerk & Greeff, 2011).

**Locus of Control.** The extent to which a family believes they are able to control a situation plays into their ability to use a problem-focused coping strategy. An internal locus of control allows a family to have confidence they have the power to control what happens whereas an external locus of control centers around the feeling that factors outside of the family have the greatest influence on the outcome. Those who embrace an internal locus of control demonstrate increased overall resilience (Bekhet et al., 2012; Greeff & Van Der Walt, 2010; McConnell et al., 2014). This is due in part to them feeling they have the capacity to control the situation and see adversity as a challenge to be overcome rather than a major barrier (Greeff et al., 2012; Muir & Strnadova, 2014).

**Religion/Spirituality.** A family's religious beliefs or spirituality play a role in their ability to cope for many families. A belief that God would not give them more than they can handle (De Klerk & Greeff, 2011) couples with providing meaning to the challenges they face, allowing them to move forward in a positive direction (Bekhet et al., 2012). Religion provides families with a way to attach meaning to the suffering they face, increasing their resilience (Greeff & Van Der Walt, 2010; Masten & Monn, 2015). Families with strong religious beliefs frequently develop stronger interfamilial relationships, increasing cohesion and the likelihood of positive outcomes (Mackay, 2003).

### *Organizational Processes*

**Support Structures.** Social support for families can come from inside or outside of the immediate family unit and can take different forms: emotional, providing information, economic, positive social interactions, affection, etc. (Armstrong et al., 2005). Instrumental or tangible support provides physical actions or objects for a family while emotional support provides encouragement and social support (Bambara et al., 2009). Both are equally important. One key factor for gauging the appropriateness of support is the difference between perceived and received support. Received support is the quantity of support given to a family while perceived support is the family's subjective view of how beneficial that support is (Chan et al., 2009).

Resiliency occurs when the level of perceived support is high (Bambara et al., 2009; Bayrakli & Kaner, 2012; Bekhet et al., 2012; McConnell et al., 2014).

**Internal Family Supports.** Communication that is open and affirmative facilitates positive outcomes for families, allowing them to increase resiliency (Greeff & Nolting, 2013; Greeff & Van Der Walt, 2010). Communication allows families to work together to find a balance between different family members' needs and responsibilities, increasing their success rate (Bekhet et al., 2012; Muir & Strnadova, 2014). This could be accomplished through stable routines and set family time (Greeff & Nolting, 2013; Greeff & Van Der Walt, 2010; Muir & Strnadova, 2014) as well as a push to make the child with a disability as independent as possible (Greeff & Van Der Walt, 2010). Without flexibility, a family is unable to allow their child/children to develop the necessary level of independence or adapt to change (De Klerk & Greeff, 2011; Muir & Strnadova, 2014). Flexibility allows families to bounce forward as they are unable to go backward; they need to be able to move on positively, changing the status quo and at the same time preserving a sense of security for their members (Walsh, 2003). At times, this flexibility can be dependent upon the flexibility of factors external to the family such as employers or childcare (Muir & Strnadova, 2014).

**External Family Supports.** External supports consist of anything that comes from outside of the nuclear family. Support systems could include extended family, friends, professionals, and other community supports such as religious institutions, and could be formal or informal. Supports could provide information and reassurance for families, provide respite care for their child, or just provide a sounding board for parents (Peer & Hillman, 2014). Strong community connections prevent families from becoming too isolated (Muir & Strnadova, 2014) as well as allowing them to maintain valued social identities even after their child's diagnosis

(McConnell & Savage, 2015). Parents with a higher educational level seek out and find more external support than those who are less educated (Greeff et al., 2012; Zegeye, 2019). Finding those external supports could be more challenging based on the community in which families reside or the age of the child, especially if they have aged out of available services (Muir & Strnadova, 2014). Providing families with a varied and far-reaching support system helps to counteract the impact of inadequate or changing services.

### ***Communication Processes***

**Coping Style.** Resiliency and coping are often used interchangeably; however, they represent separate concepts with positive coping, contributing to overall resilience when present, and making it a smaller piece of the larger resiliency concept. Coping is a cognitive and behavioral response to stress (Muir & Strnadova, 2014) and individuals employ both physical as well as social coping strategies (Masten & Monn, 2015). Different coping strategies could create either positive or negative outcomes; however, resiliency, by definition, garners a positive outcome (Fletcher & Sarkar, 2013). Therefore, coping strategies are more of a short-term, in-the-moment, problem-solving technique designed to make things better after an event has happened (Fletcher & Sarkar, 2013), whereas resiliency denotes a more long-term response allowing for positive growth and recovery from a stressor (Walsh, 2016a).

The main approaches to coping are either problem-focused or emotion-focused. Peer and Hillman (2014) described a problem-focused approach as one where families looked at the situation, analyzed the components, and created a plan to move forward. When the family embraces an emotion-focused approach, they prefer to escape from or avoid dealing with the stressor to the greatest extent possible. As situations evolve, both strategies have potential to be functional; however, a problem-focused strategy produces the best long-term results (Mackay, 2003; McConnell et al., 2014; Peer & Hillman, 2014). Bayrakli and Kaner (2012) found problem-focused coping was the single most significant factor that led to resilience in families regardless of whether or not they had a child with a disability.

**Accomplishment.** Optimism and acceptance cannot exist in a vacuum; families must be able to see at least small improvements from their efforts (Walsh, 2003). When adversity and change are seen as opportunities to grow or a challenge to overcome, resiliency develops (Greeff & Nolting, 2013; Greeff et al., 2012). Families then begin to feel they are better off than they were prior to the stressor as they found meaning and purpose in their situation (De Klerk & Greeff, 2011). As they find meaning, families also develop increased self-efficacy that affects their motivation, their ability to deal with stress, and decreases depression (Bekhet et al., 2012). De Klerk and Greeff (2011) noted that over time, a cycle emerges. As their child grows and develops, parents begin to notice the positives within their development such as perseverance, motivation, intellectual capacity, interests, and talents, causing them to develop pride in their child. As the child feels their pride, they increase their positive characteristics, creating a cycle of accomplishments.

### *Visual Impairment*

Under IDEA (2004), visual impairment is seen as any change in a child's vision that impedes their ability to function educationally even after correction. It encompasses students who have partial sight, those who are completely blind, and those with other disabilities as well as only visual impairment. Visual impairment is a low-incidence disability with less than 3% of children under 18 having a visual diagnosis that cannot be corrected by glasses (Centers for Disease Control and Prevention, n.d.). The IDEA (2004) requires that students be served within the least restrictive environment to the greatest extent possible. Students may receive services from an itinerant TVI who provides services within their home school, attend a school with a vision resource room where they receive services for part of their day, or attend a school for the blind without typical peers. The Office of Special Education Programs (U.S. Department of Education, 2021) report indicated that 68.8% of students with visual impairments were included with their typical peers 80% or more of the day. The low-incidence level of visual impairment increased the challenge for families to find the support necessary for them to develop strong resilience (Lupon et al., 2018).

Research in the area of resilience and families of children with visual impairments was limited. Existent research found that many of the same protective factors played an important role for these families. Bambara et al. (2009) stated that increased cohesion, control, and independence paired with decreased conflict led to the best family adjustment in families of children with visual impairments. The researchers emphasized that tangible, emotional supports were necessary for families to thrive and it became a balancing act to determine the type and amount of support necessary for each family member to thrive. Adequate support and information provided from professionals provided a crucial support for most families (Bambara et al., 2009; Lupon et al., 2018). Quintero et al. (2021) found that positive emotional bonds within the family and religious beliefs as well as seeking out community support helped to provide the necessary foundation to restructure families to move forward from a diagnosis of visual impairment. Active problem solving and taking an occasional step back from responsibility provided a pathway to increase long-term positive attitudes (Leyser et al., 1996). Differences existed between those families who had a child with a congenital visual impairment versus those who acquired one, and education around the visual impairment as well as encouraging the child to build upon their strengths produced better overall outcomes (Ulster &

Antle, 2005). When a child is born with a visual impairment, the family begins the process of acceptance immediately; whereas, when a child acquires a visual impairment, the child and family must work through not only the acceptance and grief but also the process of redefining who they are as individuals and a family (Tuttle & Tuttle, 2004).

## Impact of Family Resilience on Individual/Child Resilience

The level of family resiliency present shapes each individual family member as well with a greater effect on outcomes for children within the family. Children's first teachers are their families and resiliency developed in childhood could provide a lifelong buffer against stress (Khanlou & Wray, 2014). Parenting style directly influences a child's well-being and resilience (Armstrong et al., 2005). With strong parenting, even when there are increased outside stressors, children can demonstrate positive outcomes, and risks for maladjustment are greatly decreased (Mackay, 2003). The level of parental resilience/family resilience is one of the strongest indicators of child success and quality of life (Widyawati et al., 2021).

Masten and Monn (2015) found that during times of stress, parents needed to increase their care of their child to increase children's feelings of security and support. Stable routines and predictability despite upheaval allowed children to continue to explore, learn, and develop self-efficacy. Lack of these strong bonds or support led to negative outcomes for the child. The impacts of positive parenting on a child are long term and touch all areas of positive adjustment (Sandler et al., 2015). If a child does not receive the necessary support from within their home, they often look to other stable adults within their world to provide that stability; children require at least one supportive adult relationship to develop resiliency (Walsh, 1996).

## Conclusion

The definition of resiliency is an ever-moving target, changing to meet the needs of the current study or research climate; however, adversity and positive change remain important components regardless of the definition. Over time, resiliency has proven to encompass the intersection of many complex risk factors as well as protective factors, and the influence of both is dependent upon the family's perception of their impact. Resiliency cannot be taught; rather, it has to be developed over time as individuals and families face adversity and change in a positive direction. This does not mean families have been unscathed by the adversity they face; rather, they have learned from it and utilized that knowledge to move forward in a positive direction (Walsh, 2002). Recognizing that resiliency exists on a continuum families move along helps to explain why at times families appear to possess high levels of resiliency while struggling in other situations. Disability, especially a low-incidence disability such as visual impairment, provides a unique set of risk factors as well as protective factors for families. Support systems from outside the family, as well as within, provide the pieces necessary to move families forward, positively changed by the adversity they faced.

As professionals, we have a duty to assist families in finding that positive path forward by providing opportunities to strengthen the protective factors they already possess as well as introducing them to possible new protections. There is no one correct pathway to resilience; every family will forge their own way, which might look very different over time. What might be very dysfunctional for one family would provide the answer for another. It is imperative that professionals develop an acceptance of cultural differences and individual family styles to provide effective support. The research gathered here provided strong evidence that families of children with disabilities developed resiliency through a complex interplay of different protective factors when presented with adverse events. While little research existed solidifying the same is true for children with visual impairments, existent research provided a base that indicated many of the same factors were impactful. The purpose of this study was to look at the experiences of families of children with low vision to gain a better understanding of their exposure to risk factors as well as the protective factors they found most beneficial.

A phenomenological approach was used to assess factors playing into family resilience in families who have children with visual impairments. Participants selected after an initial survey completed interviews and a journaling activity to provide data to be analyzed using different coding procedures. The following chapter details the complete methodology used.

# CHAPTER III

# METHODOLOGY

Increased resiliency leads to better outlooks on life, decreased depression, greater satisfaction in relationships, and increased overall life satisfaction (Bekhet et al., 2012). Professionals in the field of education could benefit from taking advantage of the opportunity to support families in increasing their resiliency. As teachers of the visually impaired, we tend to have more contact with children than with their families; however, the resiliency demonstrated by families has a direct and lasting impact on a child's wellbeing and becomes one of the strongest influences on their later success and quality of life (Widyawati et al., 2021). Consequently, making understanding a family's resiliency a focus for us allows us to be more successful in fully reaching the child. Resiliency consists of the interplay between risk factors and protective factors experienced by families and individuals (Bekhet et al., 2012; Fletcher & Sarkar, 2013; Walsh, 2016a) and it looks very different for each family and possibly even within the same family across different stressors (Fletcher & Sarkar, 2013; Walsh, 2016a).

It is not feasible for professionals to control all risk factors present for families; therefore, the focus is best placed on strengthening protective factors instead (Bekhet et al., 2012). Every family consists of different members (parents, children, and extended family among others) and each member represents an opportunity to change the trajectory of a family's resilience. Supports such as educational opportunities, support groups, or community connections provide opportunities for increasing competency and self-efficacy within individuals and family units (Armstrong et al., 2005). Each family has a unique set of strengths and needs; therefore, a customized set of supports is required for each family (Walsh, 2003). The same is true for every disability diagnosis with each disability category presenting its own unique set of needs. Little research exists on resiliency within families of children with visual impairments, creating a void for professionals seeking to support these families effectively.

The purpose of this study was to look at the experiences of families of children with low vision to gain a better understanding of their exposure to risk factors as well as the protective factors they found most beneficial. The severity of a child's visual impairment has the capacity to change the level of impact the visual impairment has upon a family. Therefore, this study aimed to look at protective factors that resilient families of children with low vision more consistently exhibited.

## Research Questions

The following research questions guided this study:

Q1 What role do risk factors play in the experience of families of children with low vision?

Q2 What protective factors do families of children with low vision perceive to be most beneficial?

Q3 What are the challenges that families of children with low vision experience and how have they overcome them?

### Research Question 1

This question looked at those stressors present for families and how they affected their daily lives. Families could be exposed to the same stressors and each have a different response and therefore a different outcome due to the varied experience and reactions of the individual members of each family.

### Research Question 2

Question 2 provided insight into the different protective factors that families found to be most beneficial for them. Even though families might receive aid from many different avenues, only that which was perceived as beneficial would allow them to move forward positively.

### Research Question 3

This question synthesized how families took the risk factors that were present for them, combined them with the protective factors they had available, and used that combination to move forward. Due to the definition of resiliency, a dynamic process in which families utilize their strengths and resources to withstand and rebound from a crisis or adversity to move forward stronger, those families who demonstrated higher levels of resiliency would hopefully have movement in a positive direction.

## Theoretical Framework

The theoretical framework that guided the proposed study was Walsh's (2002) family resiliency theory previously discussed in Chapter II. This theory was chosen based on Walsh's focus on determining a family's existing strengths and the push to use those strengths to build capacity moving forward. Walsh focused more on the process of the interactions between risk and protective factors within families that developed resilience (Greeff & Nolting, 2013). McCubbin and McCubbin (1988) completed extensive research on family resilience as well. They based their analysis on defining the phase of adjustment or adaptation of family functions within any given time (Greeff & Nolting, 2013; McCubbins & McCubbins, 1988). They acknowledged that different factors contributed to the creation of resilience within families; however, the factors themselves were not as emphasized as the outcome (McCubbins &

McCubbins, 1988). As I sought to determine which risk and protective factors families of children with low vision exhibited, Walsh's focus on the interplay of factors was a better fit.

## Research Design

Qualitative research focuses on gaining meaning from data taken within its original context through observation, interviewing, and careful analysis (Merriam & Tisdell, 2016). One of the main tenets of qualitative research is the idea that humans cannot be distilled down to a simple group of numbers or valuable information will be missed (Laverty, 2003). There are four philosophical assumptions within qualitative research: ontology (beliefs about the nature of reality), epistemology (the nature of knowledge), axiology (how values impact research), and methodology (the process used for research; Creswell & Poth, 2018; Merriam & Tisdell, 2016). The philosophy that guides the researcher shapes and changes the nature of the research beginning with the question and moving through how the researcher collects and analyzes the data (Creswell & Poth, 2018).

## Research Genre: Phenomenology

The human experience is more complex than what can be captured in a single moment as is required in most quantitative studies (Slone & Bowe, 2014). Due to my desire to determine the essence of resiliency among families of children with visual impairments, the design I chose to use to conduct this study was qualitative and within this design, I employed phenomenology. Phenomenological research focuses on ascertaining the core of an experience without placing judgment on either the experience itself or the people involved and frequently focuses on situations that are emotionally charged (Merriam & Tisdell, 2016). The adversity necessary to create resiliency by nature often induces an intensely emotional state within families, creating an ideal fit between the methodology and the purpose of the study. Families cannot be separated from their cultural and life experience, which by nature would be different from mine. As every family demonstrates a unique pattern of both risk and protective factors and differing levels of resiliency as a result, what is functional at one time for one family might be very different from what is functional at a different time or from what I felt should produce strong resiliency. Therefore, the focus on removing bias and judgment within phenomenological research required me to put aside those biases to the extent possible and simply focus on what the participants were sharing.

Phenomenology focuses on describing the lived experience of a group of people through inquiry, reflection, creation of themes, and rich description (Creswell & Poth, 2018). The intent is to highlight what it feels like to be the person living the experience and demonstrate the connectedness of the individual with the environment around them (Finlay, 2009). Phenomenological research seeks to tease out the small pieces of the human experience that are often passed over or missed in typical research situations (Crowther et al., 2017). The purpose of this study was to look at the experiences of families of children with low vision to gain a better understanding of their exposure to risk factors as well as the protective factors they found most beneficial. The lived experience of families of children with low vision provided invaluable information about resiliency within them. Quantitative studies, where numbers and set responses become the focus, would have missed the subtleties necessary to attain this information. Phenomenology allowed for the exploration of experiences of different groups necessary to answer the questions of the impact of risk and protective factors on families of children with low vision.

Care was taken to ensure the most relevant information of the participants was pulled out through use of impressions from vocal changes, body language, and the emphasis placed by the participant on the statements. The themes found within the interviews and journal entries were interpreted to create an overall representation of what distinguishes resiliency within families who have children with visual impairments. Additional information on the steps taken to ensure trustworthiness in this study is provided later in the chapter.

## Purposeful Sampling

Purposeful sampling allows for the creation of a participant group specifically targeted toward the research questions being investigated (Merriam & Tisdell, 2016). Purposeful sampling is non-probability based and relies on the judgment of the researcher to determine the inclusion or exclusion of subjects based on the needs of their study (Creswell & Poth, 2018). Its intent is to collect a sample that reflects the average person within the target population (Merriam & Tisdell, 2016). Participants were chosen to maximize the amount of information that could be learned from them (Merriam & Tisdell, 2016). Purposeful sampling was necessary for me to obtain information specific to families of children with visual impairments. In this study, unique sampling was used to ensure that participants met specific levels of resilience to be included (Merriam & Tisdell, 2016). Due to the low-incidence of visual impairment, without purposeful sampling, enough participants to reach saturation would not have been attainable.

## Data Collection

Prior to beginning participant recruitment or data collection, I obtained approval from the University of Northern Colorado’s Institutional Review Board to conduct the study (see Appendix A). More information on the ethical considerations for this study can be found later in this chapter.

## Researcher as Instrument

Laverty (2003) indicated that Edmund Husserl developed the concept of phenomenological research because he felt strongly that humans could not be reduced to a series of numbers or reactions to stimuli, which are the core of quantitative research. He suggested that instead, researchers must look at participants in relationship to their lived experience and interactions with the world around them. As the focus is placed on more anecdotal data versus numeric, the researcher is required to play a more essential part in gathering and interpreting the data as it is no longer a matter of strict statistics. The researcher must be willing to look deeper into a person's experience to help them define it and richly describe it, all while ensuring that they set aside bias and judgment to ensure they are open to wherever the results might take them (Finlay, 2009).

Due to the potential for researcher bias to change the direction and outcome of a study, great care was taken to recognize and set aside that bias during the data collection process as well as the analysis of the data. I examined and acknowledged my bias to more thoughtfully examine the data collected and employed peer reviewing and bracketing to ensure to the best of my ability that my bias did not taint the data. This is discussed in more depth later. I strove to create open-ended interview questions free of implied judgment and instead sought to gain knowledge of the experience of each family.

## Recruitment Procedures

Recruitment occurred through contact with TVIs. I requested the Visual Impairment Service Coordinator of the Colorado Department of Education send out a recruitment email through the Colorado listserv to all TVIs in the state and reached out to individual TVIs as needed. A recruitment announcement (see Appendix B) was attached seeking connections with families of students with low vision who met certain criteria of perceived resilience and level of visual impairment. Following the initial round of recruitment, a second group of participants was recruited for this study. Rather than sending out a second list serve email, individual TVIs were contacted asking if they had any children on their caseload who would qualify. For both rounds of recruitment, TVIs were asked to consider if the children fit between the following inclusion criteria: an acuity of no better than 20/70, visual field restriction of 20 degrees or less, or a physical condition of the vision system that could not be medically corrected on one end of the continuum and dual readers on the other. If braille was their primary literacy mode, they did not qualify for this study. Children needed to have an IEP including services from a TVI. The TVIs were asked to nominate families who demonstrated the following indicators of resiliency pulled from a compilation of past research:

- They seemed to have fully accepted their child's visual impairment and embraced it;
- They were active and positive participants in the IEP process;
- They were involved in what the TVI did with their child in a positive way;
- They held their child with VI to the same standards as other children in their family;
- They gave the child with VI the same opportunities as other children in their family;
- They made connections for their child with VI with other people with visual impairments.

Families were then asked to complete a survey that contained the Walsh Family Resiliency Questionnaire (see Appendix C) along with a detailed demographic questionnaire (see Appendix D).

The last survey question asked parents if they were willing to participate in a more extensive interview where they discussed their family's experiences of having a child with a visual impairment. Fifteen families completed the survey. Final participants were chosen from those families who scored with a resiliency level of at least a four on the questionnaire and indicated a willingness to continue in the study. Following the first interview, families were asked to complete journal prompts; a second interview was conducted to follow up on ideas initiated in the first interview as well as the journal and to explore more deeply common themes among the participants.

## Participants

Participants in this study were the parents, guardians, or caregivers of children with low vision. Ten families were interviewed with the goal of reaching saturation. The definition of visual impairment used for this study was taken from typical criteria used to qualify a student with a visual impairment for IEP services in Colorado: a near or distance acuity of no better than 20/70 corrected vision in the better eye, a visual field restriction of 20 degrees or less, or a physical condition of the visual system that could not be medically corrected. This could encompass a variety of different visual conditions including but not limited to cortical visual impairment and progressive visual conditions where the child might currently have more usable vision and a prognosis of more vision loss. This definition was chosen as it represented the most common defining criterion used to identify students for IEPs within school districts. To participate in this study, the child had to have an education impact from their visual impairment and be receiving services from a TVI. For this study, the continuum of low vision covered children who met the initial definition of visual impairment to those who were dual readers. As soon as a student was a primary braille reader, they no longer qualified as low vision under this study. Families of children with visual diagnoses such as convergence disorder, strabismus, or amblyopia were excluded from the scope of this study. This was due to difficulty in determining an accurate causal connection among these diagnoses and an educationally relevant impact. Families of children with vision in only one eye met the inclusion criteria if the vision in their remaining eye was impacted enough to fit the above criteria. If the vision in their remaining eye did not meet these criteria, they were excluded from this study.

Priority for selection was given first to families of children without additional disabilities. As not enough families of children without additional disabilities were nominated, the inclusion criteria were widened. One of the families in the study had a child who had cerebral palsy along with her visual impairment and two families had children who had a concurrent diagnosis of level one autism.

Resilience is seen as a process or a journey rather than a destination and a continuum rather than a single event; therefore, resilience is not cumulative, it is situational (Greeff & Nolting, 2013; Khanlou & Wray, 2014; Migerode et al., 2012; Walsh, 2016a). A family who showed great resilience at any given time might not when a new stressor is introduced to their situation due to the large variety of factors that work together to produce resilience (Fletcher & Sarkar, 2013). For this study families of children with low vision of any age or date of onset were used as they were all nominated as resilient by their TVIs. All self-reported high levels of resilience on the Walsh Family Resiliency Questionnaire, making the age of their child irrelevant. Information was gathered on each of these areas for comparative purposes; however, they did not lead to exclusion from participation. The final participants included one family of a child involved in early intervention, six families with school-aged children, one family of a graduating senior, and two families with children who had graduated and were in their early 20s. Seven participants received the diagnosis of visual impairment very soon after birth, two families received their diagnosis when their child was four or five, and the final participant received their diagnosis when they were in early elementary school. The participants had children of all ages and therefore varying levels of exposure to risk factors due to the length of time they had been living with their visual impairment. However, they all scored at least a level four on the complete Walsh Family Resiliency Questionnaire and all had been exposed to multiple risk factors and developed strong protective factors that allowed for common themes to be developed in answer to the research questions.

The participants themselves were parents, guardians, or caregivers of children who had low vision. To participate, the adult had to live with their child with a visual impairment the majority of the time during their formative years. This ensured that the level of resilience within their family was the one that was most impactful for their child as they developed. In the case of the older children, one still lived at home as she had cerebral palsy as well as her visual impairment and the other was finishing her senior year at the University of Colorado. However, they had both lived with the parent participants throughout their school-aged years. The teacher of the visually impaired working with the child nominated them for participation based on their perceived level of resilience in accordance with a detailed inclusion criterion (see Appendix E). The goal of this study was to gain enough participants to reach saturation within the interviews. Saturation was reached when no new information was obtained from participants and responses became redundant (Merriam & Tisdell, 2016). If saturation had not been met within the first 10 participants, more participants would have been recruited for the study. However, I felt I was able to reach saturation with the 10 chosen participants after conducting two interviews with each family. Table 1 contains basic demographic information for the participants in this study and is followed by a more detailed description of each participant.

The participants in my study came from varied backgrounds, although many of them had a background in education in some form. Seven of the participants had master’s degrees and the remaining participants had either a high school diploma or associate’s degree. Seven of the families were biological families of the children with low vision living with both parents, one family was the biological mother with a stepfather due to the death of the child’s biological father, one family was the biological mother with a stepfather due to divorce, and the last participant was a mother who was divorced. The mothers within the family completed all the surveys, interviews, and journal questions. Participants ranged in age from 26 to 60 years old. Nine of the participants were Caucasian and one was Asian. The 10 participants in this study were Helen, Sally, Emily, Mikayla, Margie, Ann, Evelyn, Ava, Sarah, and Grace. All participants were given pseudonyms to protect their real identities. The next section describes each participant from data collected from the initial demographic survey as well as interviews.

**Table 1**

*Basic Demographic Information*

| Participant | Age of Participant | Ethnicity | Education Level | Age of Child | Eye Condition | Overall Score |
|---|---|---|---|---|---|---|
| Helen | 42 | Caucasian | Master’s degree | 12 and 15 | Retinitis Pigmentosa | 4.2 |
| Sally | 46-55 | Caucasian | Master’s degree | 11 | Aniridia, foveal hypoplasia | 4.6 |
| Emily | 26-35 | Asian | Master’s degree | 2 | Oculocutaneous albinism type 4 | 4.4 |
| Mikayla | 46-55 | Caucasian | Associate’s degree | 22 | Leber’s Congenital Amaurosis | 4.5 |
| Margie | 46-55 | Caucasian | Master’s degree | 21 | Optic atrophy, amblyopia, and myopia | 4.4 |
| Ann | 36-45 | Caucasian | Master’s degree | 10 | Aniridia | 4.1 |
| Evelyn | 54 | Caucasian | High school/Associate’s degree | 12 | Aniridia, glaucoma, cataracts & photophobia | 4.0 |
| Ava | 36-45 | Caucasian | Master’s degree | 10 | Microphthalmia in left eye, optic nerve dysplasia, coloboma, dragged retina in right eye | 4.33 |
| Sarah | 60 | Caucasian | Master’s degree | 18 | Aniridia | 4.88 |

| | | | | | | |
|---|---|---|---|---|---|---|
| Grace | 46-55 | Caucasian | High school/Associate’s degree | 17 | Retinitis Pigmentosa | 4.0 |

### *Helen*

Helen has two children ages 12 and 15 who both have a diagnosis of retinitis pigmentosa (RP). Her older daughter received her diagnosis at age five and has been receiving services since then, about 10 years. After her older daughter was diagnosed, they understood the genetic component involved and saw signs of the same issues in their younger daughter when she was three. However, they did not choose to have her formally diagnosed until age five as they had had a negative experience with the process from when their older daughter was diagnosed and wanted their younger daughter to be able to be a more active part of the process before they submitted her for testing. They also felt like she was not at a point where she needed services or would miss out without the diagnosis. The family took a very active role in understanding their children’s visual impairments as well as seeking out services. While both children have the same diagnosis, their progression has been very different, and they are at different points on their journey with each child. Helen is a music teacher and has worked in education for around 17 years. Helen’s family had an overall score of 4.2 out of 5 on their resiliency questionnaire with a 4.4 in belief systems, a 4.1 in organizational processes, and a 4.2 in communication processes.

### *Sally*

Sally is the divorced mother of two daughters, the older daughter is 12 and a half and the younger daughter, who has aniridia, foveal hypoplasia, and nystagmus, is 11 years old. Sally has a graduate certificate in restorative practices and as a family, they work hard to incorporate everyone’s needs and wants into the family unit. The girls spend half of their time with their father where there is a very different set of expectations and interaction types. Sally feels as if the girls are beginning to use what they receive at her house to help ground them while they are with dad as well. Sally has currently taken a leave of absence from her teaching job while she determines which direction she would like to move in next. Sally's family had an overall score of 4.6 out of 5 on their resiliency questionnaire with a 4.5 in belief systems, a 4.5 in organizational processes, and a 4.7 in communication processes.

### ***Emily***

Emily is the mother of two young children; her son is five and her daughter, who has oculocutaneous albinism type 4, is 2. They began to notice some nystagmus when she was three months old and have been working through the process of identification and managing services since then. Having such a young family presents with its own set of challenges. Emily works within the early intervention system herself and feels her background has made it easier for her to navigate the world she finds herself in now with her daughter. Because of having her daughter, she has now chosen to go back to school to become a teacher of the visually impaired (TVI). Emily's family had an overall score of 4.4 out of 5 on their resiliency questionnaire with a 4.5 in belief systems, a 4.2 in organizational processes, and a 4.5 in communication processes.

### ***Mikayla***

Mikayla has three daughters. The oldest is 24, her middle daughter, who has Leber's congenital amaurosis, is 22, and her youngest is 17. Her older two daughters are from her first marriage. After her husband passed away, she married again and they had their third daughter. They began to notice some differences in their daughter's vision when she was four months old; however, she was diagnosed as just having amblyopia, and therefore the insurance would not cover further assessment. When she was four, their insurance changed and they were able to have further testing, leading them to discover the Leber’s diagnosis. Mikayla was able to stay at home with her children, only returning to work part-time when they were in high school. Mikayla’s family had an overall score of 4.5 out of 5 on their resiliency questionnaire with a 4.6 in belief systems, a 4.7 in organizational processes, and a 4.2 in communication processes.

### ***Margie***

Margie has three children. Her youngest daughter is 10 and her oldest children are 21-year-old boy/girl twins. Her twin daughter has cerebral palsy, optic atrophy, amblyopia, and myopia. They initially noticed strabismus and esotropia and she had surgery to correct it when she was about 13 months old followed by patching. They did not realize until much later that she had more complex visual issues so she did not begin to receive services from a TVI and orientation and mobility specialist until she entered kindergarten. She uses a power chair for mobility, has slightly impacted fine motor skills, and low average cognitive skills. Many of the barriers the family faces are related to her physical disability rather than her visual impairment. Margie remained at home with the children to help with her daughter’s care, only going back to work part-time when she was older. Margie’s family had an overall score of 4.4 on the resiliency questionnaire with a 4.2 in belief systems, a 4.7 in organizational processes, and a 4.2 in communication processes.

### ***Ann***

Ann has four children. Her oldest daughter is from a prior relationship and has aniridia, a diagnosis she inherited from her father who is also visually impaired. Her husband has two children from his first marriage and together they had a fourth child. Ann has primary custody of her daughter but she spends time with her father as well. Her daughter is twice exceptional so she receives services not only for her vision but enrichment for her giftedness as well. She is a dual reader, who mainly reads in print within the classroom, but she is learning braille preemptively in case she has more vision loss as time goes on. Ann chose to go back to school when her daughter was young to become a TVI. Ann's family had an overall score of 4.1 on the resiliency questionnaire with a 4.25 in belief systems, a 4.1 in organizational processes, and a 4.0 in communication processes.

### ***Evelyn***

Evelyn's family was unique within this study as visual impairment was very prevalent throughout the family. She has aniridia herself and lost all vision 14 years ago. Her current partner has aniridia as well and her grandma and aunts are also visually impaired. She is the mother of seven children. Four of those children, from a prior relationship, are all fully sighted and no longer live at home. Currently, she and her partner have three children. Her oldest from the second relationship is 19 and is deaf/blind with other developmental disabilities due to the combination of the different aniridia genes he received from his parents. Her 17-year-old is fully sighted. Her child with low vision is 12 and has aniridia as well as level one autism; his aniridia was diagnosed at birth.

Evelyn remains at home to care for her children. Her son receives services from a TVI as well as an orientation and mobility instructor. He is a dual reader, reading in both print and braille; he mainly uses print within the classroom and is learning braille in case he loses more vision later in life. His autism impacts his social interactions but that does not prevent him from remaining on grade level within a fully inclusive classroom. Evelyn's family had a score of 4.0 on the resiliency questionnaire with a 4.0 in belief systems, a 4.0 in organizational processes, and a 4.0 in communication processes.

### ***Ava***

Ava has two children; her oldest is 12 and her youngest is 10. Her youngest was diagnosed at birth with microphthalmia in his left eye, optic nerve dysplasia, coloboma, and dragged retina in his right eye. He got his first prosthetic eye on his left side when he was a year and a half old and has worn one since. Ava is a classroom teacher. She took time off work when her youngest was born to manage all the different medical and therapy appointments, went back part-time when he entered school, and just returned to the classroom full-time this year. Ava's family had an overall score of 4.33 on the resiliency questionnaire, a 4.1 in belief systems, a 4.8 in organizational processes, and a 4.1 in communication processes.

### *Sarah*

Sarah has two children. Her oldest is 18 and just recently graduated from high school. He has a diagnosis of aniridia, which was given at birth. Her daughter is 15. Sarah and her husband are both in the field of education and spent considerable time overseas doing relief and development work. They were in Afghanistan when she became pregnant with her son. They returned to the United States for her to have him and stayed for a short time to learn how to begin to help with his visual impairment, returning to Afghanistan when he was 10 months old. They moved back and forth between overseas and the United States until her son was ready to enter school. Sarah's family had an overall score of 4.88 on the resiliency questionnaire, a 4.8 in belief systems, a 4.8 in organizational processes, and a 5.0 in communication processes.

### *Grace*

Grace is the mother of two daughters—her younger daughter is 14. Her oldest daughter is 17 and has a diagnosis of McKusick-Kaufman syndrome, which was given at birth. As a part of that, she has retinitis pigmentosa as well as autism spectrum disorder. Her autism is highly impactful on her social communication as well as behavior; however, she is twice exceptional so she requires extra challenge in the area of math and science. Her vision has been monitored since birth due to the high likelihood of retinitis pigmentosa but she did not have a visual impact requiring services until fifth grade. She receives services from a TVI and orientation and mobility specialist and is learning braille in case she loses more vision. Grace's family scored an overall 4.0 on the family resiliency questionnaire. They had a score of 4.1 in belief systems, 3.8 in organizational processes, and 4.1 in communication processes.

## Data Collection Procedures

### Initial Survey

After families were nominated by their TVI and had agreed to participate in the study, they were sent an initial survey consisting of detailed demographic information as well as the Walsh Family Resiliency Questionnaire (see Appendices C and D). I chose The Walsh's Family Resiliency questionnaire based on its strong reliability and validity and how well it addressed many different facets of family resiliency.

The Walsh Family Resiliency Questionnaire was developed in 2006 by Dr. Forma Walsh based on the perspective that families provide the foundation for adaptive resources and overall coping (Duncan et al., 2021). The questionnaire provides families with the opportunity to self-report on their perceptions of how their family manages adversity and the protective factors they are supported by Walsh (2016b). The intent of the questionnaire is to provide a map of a family's resiliency, keeping in mind that levels of resiliency can change over time and are not fixed (Walsh, 2016b). Each question is answered using a Likert scale from 1-5 for families to self-report their perceived level with each topic presented with a 1 representing *rarely or never* and a 5 representing *almost always*. Scores are then summed; the higher the score, the higher the current level of resiliency (Duncan et al., 2021). Level 4 was chosen as the cutoff for this study as it represented the higher end of resiliency without having to be perfect. Permission was received from Dr. Walsh to use her questionnaire (see Appendix E).

Duncan et al. (2021) studied the Walsh Family Resiliency Questionnaire to examine its reliability and construct validity. They found the psychometric properties were sufficient to indicate it did indeed measure family resilience. Cronbach's α for the three subsections (belief systems, organizational processes, and communication processes) ranged from .85 to .90, indicating high levels of agreement among the questions. Overall, they found the questionnaire to have both high reliability as well as construct validity.

## Interview Data

Following the completion of the initial demographic and resiliency questionnaire, I chose participants for this study based on their responses on the demographic data, the level of reported resiliency within their family, and their willingness to continue in the study. I selected 10 participants to interview from families of children with low vision. Interview questions were created by looking at past research, the risk and protective factors that played a role for those families, as well as looking at the different subsections of the Walsh (2002) family resiliency theory and basing questions on those subsections. Follow-up questions for the second interview were created after coding the first interviews and journal prompts; they included different questions for each family based on the need to gather more information about particular risk or protective factors for their family. The interviews began with establishing rapport and gaining a basic knowledge about the family. They then delved deeper into the risk factors present for the family as well as more detailed descriptions of the protective factors they utilized. Each initial interview lasted around 60 minutes. After initial analysis of the first interview and reviewing the journal entries, I conducted a second interview with all participants. This interview was based on expanding on what they shared in the first interview and the journal as well as incorporating new questions based on common themes I had found across the data. Second interviews lasted an average of 30 minutes.

Interviews were conducted using the video conferencing platform Zoom and were audio and video recorded with permission from the participants for later transcription. Transcription of interviews was provided by the Zoom platform. I went back through the recordings and compared them to the transcripts to ensure the transcription was accurate. Recording of the interviews allowed me to go back and access the nonverbal communication provided by the participants as well as their verbal contributions to help ensure I did not miss anything during the initial interview. All recordings, transcriptions, and notes will be stored in a password-protected folder on my computer, not on the web, for three years.

Throughout the interview process, I strove to create more of a conversational environment rather than a question-and-answer session. This increased the likelihood I received more honest answers and created an environment in which I was able to gain knowledge based on the interaction between myself and the interviewee (Creswell & Poth, 2018). Semi-structured questions allowed me to guide the conversation toward information relevant to my research questions while at the same time providing enough latitude to allow participants to take the conversation in the direction they found to be the most relevant (Merriam & Tisdell, 2016). I strove to form initial questions in a way that did not hint at a predetermined answer to those questions but rather allowed participants to interpret the question and subsequent answer in their own way (Emiliussen et al., 2021). Initial interview questions were aligned with the Walsh (2002) family resiliency theory as well as the stated research questions. Questions for the second interview were designed to ensure no information was missed in the first interview as well as to probe areas brought up by other participants in the first set of interviews. As much as possible, follow-up questions were drawn from what the participants themselves stated rather than a predetermined list of questions (Laverty, 2003). Interview questions can be found in Appendix F. The goal of the interviews was to determine which risk factors were present for families as well as what protective factors they employed and how they employed them.

### Participant's Journals

Journaling denotes the practice of having participants record their thoughts and feelings about a given topic either as the events are occurring or after the fact (Creswell & Poth, 2018). The intent of a journal is to blend together not only the facts of the situation but also what the participant thought and felt about the situation (Hayman et al., 2012). Journaling is often used within a study to supplement the information gained through interviews (Creswell & Poth, 2018; Hayman et al., 2012). While there are some drawbacks to journaling, such as decreased participation and confusion around what to include, these could be avoided with thoughtful preparation (Hayman et al., 2012).

I asked parents to complete short journal entries following the first interview to ensure I gathered all the necessary information and did not miss anything they wanted to share after further reflection. The journal entries were set up to answer specific questions (see Appendix G). Families received instructions on how to complete the journal after the interview and were allowed to ask any questions they might have had about the process. Each journal entry was coded similarly to the interview questions and became a part of the data analysis process.

### Field Notes

Field notes are intended to capture the "in the moment" impressions and observations completed by the researcher to provide richer details about the situation being studied (Merriam

& Tisdell, 2016). Field notes in qualitative research supplement and confirm the data received through other sources to increase the evidence base (Creswell & Poth, 2018). Directly following each individual interview, I journaled about my impressions around what was said both verbally and nonverbally, ideas and questions that were raised throughout the discussion, and my overall thoughts about how the conversation went and if enough information was gathered. I used my field notes to assist me with the bracketing process by recording my immediate impressions and acknowledging when they triggered my bias. This helped with creating the questions asked in the second interviews as well. My journal with field notes contains a detailed record of the process I went through to complete my research.

## Data Analysis Procedures

Data analysis within a qualitative research study is a spiraling process where the researcher continually returns to earlier parts of the process to address new data (Creswell & Poth, 2018). When analyzing qualitative data, the process occurs simultaneously with the collection of the data as well as continuing after collection, unlike a quantitative study where all data are collected prior to the beginning of analysis (Merriam & Tisdell, 2016). The process of analysis involves looking closely at individual pieces of data, determining common themes, and organizing those themes into the results of the study (Creswell & Poth, 2018; Merriam & Tisdell, 2016).

I analyzed the data in this study through the use of coding. Coding was completed using three levels: open coding, axial coding, and selective coding. Open coding occurs first and at this point in the process, everything is considered. The data are read line by line and impressions are recorded in words or phrases using as much of the participants' own words as possible (Merriam & Tisdell, 2016). As I recorded my impressions, I created smaller categories of information within the transcribed interviews and journal entries and assigned each category a code, making sure I did not have an excessive number of different codes and pulling out participant’s exact words to ensure credibility (Creswell & Poth, 2018). Throughout the process, I kept detailed notes about my thoughts, impressions, and any observations I made in my field notes (Merriam & Tisdell, 2016).

Axial coding follows open coding. During this step in the process, each open code is analyzed and grouped with others to determine relationships between the data collected. (Merriam & Tisdell, 2016). Patterns become important at this stage. This requires careful detection of the salient features within data to provide an invaluable connection between the different data collected. Some interpretation naturally occurs as a means to find meaning through the use of common knowledge, insights gained from a literature review, and knowledge of the phenomenon being studied (Barrett, 2007). I organized my original codes into meaningful clusters with the aim of answering my research questions.

Selective coding occurs following all other stages. In this part of the process, the central theme of the research is related to all the codes and themes found, and the relationships are reinforced (Creswell & Poth, 2018). This step is what allows the researcher to validate the conclusions to which they have come. Participant quotes could be collected throughout the coding process to help strengthen the final argument. After completing my open and axial coding, I compared the results to my initial research questions and organized the results in a way that answered those questions.

As there were two sets of participants for this study, the results from the second set of participants were coded using deductive coding as completely removing all knowledge of the first set of data was impossible. Deductive coding entails applying already created codes to new data (Barrett, 2007). Although already existent codes were used, I was careful to keep open to the idea that new codes could be generated as well.

A peer reviewer assisted with the initial coding process. We coded six interviews (roughly 25% of the data) together, ensuring our coding matched. We discussed any differences of opinion we had and worked to reach consensus. This helped to safeguard against biased coding. More information on this process and the use of the peer reviewer is provided later in this chapter. Table 2 shows a table adapted from Creswell and Poth (2018) outlining my process.

**Table 2**

*Data Analysis*

| Data Analysis and Representation | My Study |
|---|---|
| Managing and organizing the data | I watched each video to ensure that the transcription matched the interview and organized the transcripts from all of the interviews and journals into sets to ensure the transcripts from each family were kept together |
| Recording emergent ideas | As I read through the transcripts, I took notes and created memos of different impressions and codes |
| Describing and classifying codes into themes | I looked at all the different codes I created and determined how they described the essence of resilience within the families in the study and created statements detailing the different components. |
| Developing and assessing interpretations | I organized the statement into meaningful units that detailed the similarities and differences between protective factors present within the study. |
| Visualizing the data | I created a rich description of the themes that have emerged and tied them together into an overall view of the essence of resiliency within families of children with visual impairments. |

## Trustworthiness and Credibility

Trustworthiness of the study speaks to the reliability and validity of a qualitative study (Creswell & Poth, 2018). Does the study really capture the essence of what it intends to measure and would it be possible to recreate the study again or apply the results to other situations (Merriam & Tisdell, 2016)? There are many different ways to incorporate trustworthiness into a qualitative study but the end goal is to ensure the accuracy of the results (Creswell & Poth, 2018). Participants should be able to see their opinions and feelings reflected in the analysis, even when the researcher is not quoting them verbatim (Merriam & Tisdell, 2016). Due to changes in the human experience and our perception of it, a qualitative study could never be reproduced exactly even if the same researcher and participants were used (Merriam & Tisdell, 2016). Therefore, it is imperative that the interpretation of the data is well supported by that data. Within this study, I analyzed my personal bias by employing bracketing, utilizing member checks, triangulating the results, and employing peer reviewing or debriefing to increase the trustworthiness of the study.

### Personal Bias

Throughout the process, I was aware of my own biases and thoughts about the situation to put them aside and interpret the data in the most unbiased way possible (Merriam & Tisdell, 2016). Unbiased analysis not only allowed me to represent the voices of the participants more accurately but did change my perceptions slightly as both a researcher and practitioner (Finlay, 2009). Unbiased analysis was accomplished to the extent possible through the process of bracketing. In addition, I used a peer reviewer to go through transcripts and field notes from each interview and review emerging codes and themes.

I have worked closely with families as a TVI and orientation and mobility specialist for 15 years and prior to that as an occupational therapist for 10 years. During that time, I provided services within the home, in a preschool setting where we worked closely with families to develop home programs, and in a Pre-K to transition environment. I have always felt strongly that collaboration with families is imperative to facilitate lasting change or progress for my students. I have worked in a fully transdisciplinary model alongside social workers, psychologists, learning specialists, speech therapists, deaf and hard of hearing teachers, occupational therapists, physical therapists, classroom teachers, and other professionals to provide the most cohesive programing possible for children and their families. My focus since entering my doctoral program has been on how to best support the social emotional needs of my students and their families, which led me to research resilience within families extensively. I was unable to separate myself from this background while conducting interviews; however, I did not share the majority of my background with the participants during the process.

In thinking about my bias on resiliency, I discovered I was fascinated by the components involved in resiliency and in social emotional/mental health issues in general. I felt strongly that without a strong base and positive mental health, a child will be unable to truly succeed in life. I grew up in a home where my mother demonstrated very strong resiliency. We never had much money but we always made the best of what we had. She modeled for us how to sing through the hard jobs, persist until we had finished, and problem-solv any situation. I took away from her the idea that as long as you were ready and willing to be creative, you could solve anything. We were also brought up with a strong belief in God and the idea that He had a plan for us so that even setbacks were a part of that plan that we would understand later.

I am fiercely independent and introverted so I have had to work very hard at the idea that I can, or should, accept help from others, though I am willing to help someone else at the drop of a hat. I see the world through a series of gray lenses rather than black and white and struggle a little when others need more black and white situations. Being introverted makes open communication a little more challenging in most situations, especially if there is a higher emotional level involved. I would say that for the most part I have fairly high levels of resiliency; however, there are definitely times when I sit back for a moment and lament the fact I am in such an adverse situation before I can take a breath and move forward.

When I think of resiliency and the students I teach, I am very struck by the strong influence familial resilience has on the student’s capacity to deal with adversity. Those parents who have found a way to embrace their child’s visual impairment and move forward seeking information and assistance most often have children who demonstrate increased resiliency. When I see parents who are struggling to accept their child’s visual impairment or simply struggling with life in general, I see the same tendencies mirrored within the children. At times, I struggle with the strong influence an adult’s coping skills and decision making has over their children. This can lead to me judging families due to their decreased resiliency and the negative impact it has on their children. I am very aware of this bias and to address it I consciously go to a place of curiosity when interviewing families and approach it as a puzzle to be solved rather than a situation to be judged.

## Bracketing

Bracketing refers to the process through which everything from the outer world and all preconceived ideas about the subject are set aside to focus solely on the essence of the experience (Laverty, 2003). No judgment is applied to the data and no theories are formed before seeing what all the data provide (Finlay, 2009). By setting aside any bias to the best of my ability, I became open to what the experience itself was saying (Merriam & Tisdell, 2016). Of course, no one can completely set aside their past experiences so the goal should be to be aware of the past so it does not color the analysis of the current situation (Creswell & Poth, 2018). I examined and disclosed my personal bias in relation to resiliency as well as working with families who demonstrated differing levels of resiliency and worked to set aside those biases as I coded and organized the data into themes. While conducting interviews, coding journal entries, and coding interview transcripts, I utilized my field notes. I recorded impressions I had as well as instances where my bias was triggered to be aware of it and more easily set it aside when coding. Peer-reviewing of my coding helped to ensure I had been successful in setting aside my bias.

Bracketing became more important during the second set of interviews to ensure I was not predetermining what risk and protective factors would be present for families. I needed to go into each interview making sure to ask the same open-ended questions as I did in the first set of interviews, as well as making sure to follow up on all new directions the participants mentioned.

## Triangulation

Triangulation works toward increasing the credibility of a study by looking at the research questions through the lens of multiple forms of data (Merriam & Tisdell, 2016). Information from each data source was individually analyzed and the resultant themes were compared to ensure they all supported the same trends across the data collected (Creswell & Poth, 2018). The three data sources I used within this study were the Walsh Family Resiliency Questionnaire, two separate interviews, and participants' journal entries. The answers given on the questionnaire were summed and the higher the score received, the higher the level of reported resiliency. The questionnaire was divided into the three domains of the Walsh (2002) family resiliency theory, which allowed me to make direct comparisons between responses on the questionnaire and those received from interviews and journaling. I transcribed and coded the first interviews prior to coding the journal entries, and then completed coding of the second interview. After completing coding, I compared the three sets of data to develop common themes. Throughout the process, I referred back to the data collected in the initial survey to determine if the answers given during the interviews and journal entries correlated with the information given in the survey responses. The presence of similar data across all three sources increased confidence the correct conclusions were met.

### Peer Reviewing

Peer reviewing consists of having another professional who is familiar with qualitative research double check my coding and analysis of themes to make sure my analysis was feasible based on the data present (Merriam & Tisdell, 2016). Due to the large amount of data from the two interviews and journal entries, this was especially important for this study. My peer reviewer was a fellow Ph.D. candidate from the University of Northern Colorado who had experience with qualitative research. She had also been a TVI for over 10 years and had extensive experience working with families with children with VI. Transcripts from interviews were shared with her.

We independently coded six interviews (about 25% of the data). After completing initial independent coding, we came together to compare the codes we assigned and came to an agreement on the importance and relevance of the information shared and the codes assigned. While the wording of our initial coding did not match exactly, the general theme behind it did. I looked at our differences in wording, compared it to what I had found in the research as well as how we coded other sections of the interviews, and adjusted accordingly. I then continued to apply similar coding to the remainder of the interviews and journal entries. When presented with the second set of data, we discussed making sure we were both open to finding new themes or ideas within that data as well. We came together again after I compiled the original open codes and looked at how to group them. As resiliency was a new area of focus for my peer reviewer, we spent more time talking through the research as well as Walsh's family resiliency theory so she would have a better background with which to approach the axial coding. From there, we discussed and agreed upon the common themes present in both the risk factors and protective factors within the study. Having this extra layer of analysis helped to increase the validity of my study.

## Member Checking

Member checking involves returning the data you have collected and analyzed to the participants to have them confirm it accurately represented their thoughts and feelings (Creswell & Poth, 2018). This helps to lessen the possibility of researcher bias within the data analysis. For this study, each interview was recorded and transcribed with participants' permission. Transcripts of each interview were shared with the participant via email. They were given one week to review the transcripts and inform me of any changes they wanted to make. As all participants indicated there were no changes, I proceeded to code the interviews.

## Ethical Considerations

All participants were adults who were provided with background information on the purpose of the study, possible risks as well as possible benefits, and allowed to ask whatever necessary questions prior to signing consent. As part of the Institutional Review Board approval process, all potential risks to participants were disclosed to them within the informed consent letter they signed prior to participating in the study (see Appendix H). Most of my questions focused on the risk factors present and the protective factors that had been beneficial for participants; however, there was no way to predict every direction an interview would move in so there might have been some topics raised that could be distressing to some participants. The potential risks included the possibility of psychosocial distress from having to discuss situations that were by nature filled with adversity. The consent form included contact information for 211, a resource for either a onetime chat or connection to a more long-term mental health treatment option in case participants felt the need to reach out for support after participation.

All study materials such as survey results, consent forms, audio/video recordings, and journal entries have been kept confidential and stored in a password protected folder on my computer not on the web. While it is impossible to guarantee complete confidentiality, all possible precautions were taken to prevent breaches in confidentiality. Every participant was assigned a participant number and had the option to choose how they were referred to. Data were seen by only me and the peer reviewer. All materials from the study will be destroyed after a period of three years. The study protocol is summarized in Table 3.

**Table 3**

*Study Steps and Procedures*

| Step | Description/Data Collection | Research Questions Addressed |
|---|---|---|
| Institutional Review Board approval | Approval from the University of Northern Colorado | |
| Recruitment of participants | Recruitment occurred through nomination by teachers of the visually impaired | |
| Completion of initial survey | The initial survey included simple demographic questions as well as the Walsh Family Resiliency Questionnaire | Questions 2, 3 |
| Choosing of final participants | Final participants were chosen from those who demonstrated high resiliency and agreed to continued participation. | |
| Completion of initial interviews | Interviews were conducted and recorded to determine which protective factors impact families of children with visual impairments. A second interview was conducted following the coding of the initial interviews and journal entries. | Questions 1, 2, 3 |
| Completion of journal entries | Following initial interviews, journal prompts were sent to ensure that no information was missed in the initial interviews. | Questions 1, 2, 3 |
| Coding of data | Data were coded using open axial and selective coding with the use of a peer debriefer to ensure nothing was missed and bias was limited. | Questions 1, 2, 3 |

| | | |
|---|---|---|
| Summary of results | The results were summarized to provide answers to the research questions. | Questions 1, 2, 3 |

## Conclusion

The aim of this phenomenological study was to gain a deeper understanding of the lived experiences of families of children with low vision who experienced higher levels of resiliency. Throughout the study, I looked closer at resiliency within families of children who had low vision, paying particular attention to how protective factors were involved as well as any common risk factors. The phenomenological approach allowed me to become immersed within the phenomenon of resiliency in an open and nonjudgmental way to truly see the many different sides that presented themselves within each family.

An initial survey looking at overall family resiliency as well as pertinent demographic information provided the initial data source. Further participation depended on participants' responses to the initial survey based on their level of family resilience. Interviews consisted of gaining information specific to participants' families. They explored risk factors that might be present as well as their perception of the utility of various protective factors for their families. Participants were asked to complete short journal entries following their initial interviews to ensure no information was missed and to give them an opportunity to share any other thoughts they might have. Following the journaling, a second interview was conducted to further ensure no information was missed.

Data collection consisted of results from the recruitment survey, transcripts from interviews, and journal entries. While applying bracketing techniques, I coded the data into common themes and compared those among the three different data sources. I then compared and contrasted the data obtained from different sources to answer the following research questions:

Q1 What role do risk factors play in the experience of families of children with low vision?
Q2 What protective factors do families of children with low vision perceive to be most beneficial?

Q3 What are the challenges that families of children with visual impairments experience and how have they overcome them?

Peer reviewing, member checks, and triangulation assisted with ensuring my bias remained out of the analysis and the results of the study reflected the views of the participants.

# CHAPTER IV

# RESULTS

This qualitative study explored the lived experience of families of children with low vision. The purpose of this study was to look at the experiences of families of children with low vision to gain a better understanding of their exposure to risk factors as well as the protective factors they found most beneficial. Ten mothers of children with low vision completed a survey, two interviews, and a set of journal prompts addressing their family's resiliency. Open-ended interview questions and journal prompts collected comprehensive information about families' experiences. To address what risk factors and protective factors played a role for families, the following research questions were posed:

Q1 What role do risk factors play in the experience of families of children with low vision?

Q2 What protective factors do families of children with low vision perceive to be most beneficial?

Q3 What are the challenges that families of children with visual impairments experience and how have they overcome them?

This chapter presents common themes that emerged from the data after coding both interviews and journal responses and comparing them to the survey results. Quotes supporting these themes resulted from a combination of journal entries and first and second interviews. Five categories emerged from the data for research question 1: (a) unsupportive professionals, (b) trust, (c) finding a place, (d) societal perceptions, and (e) uncertainty. Thirteen themes emerged from the data for research question 2. For analytical purposes, they were organized into three categories based on Walsh’s family resiliency theory: belief systems, organizational processes, and communication processes. The themes within belief systems were (a) positive outlook, (b) acceptance of visual impairment, (c) locus of control, and (d) religion. Themes within organizational process were (a) advocacy and information gathering, (b) outside support, (c) supportive professionals, and (d) technology. Themes within communication processes were (a) goal setting, (b) changing relationships, (c) communication, (d) self-care, and (e) problem solving. Research question 3 was answered by a synthesis of the themes found for research questions 1 and 2. Table 4 shows the categories and themes related to each research question.

**Table 4**

*Categories and Themes*

| Research Question | Category | Theme |
|---|---|---|
| RQ1: What role do risk factors play in the experience of families of children with low vision? | Risk Factors | Unsupportive professionals<br>Trust<br>Finding a place<br>Societal perceptions<br>Uncertainty |
| RQ2: What protective factors do families of children with low vision perceive to be most beneficial? | Belief Systems | Positive outlook<br>Acceptance of visual impairment<br>Locus of control<br>Religion |
| | Organizational Processes | Advocacy and information gathering<br>Outside support<br>Supportive professionals<br>Technology |
| | Communication Processes | Goal setting<br>Changing relationships<br>Communication<br>Self-care<br>Problem solving |
| RQ3: What are the challenges that families of children with visual impairments experience and how have they overcome them? | Unsupportive Professionals | Advocacy and information gathering<br>Outside support<br>Changing relationships<br>Acceptance of visual impairment<br>Locus of control<br>Supportive professionals<br>Problem solving |
| | Trust | Locus of control<br>Supportive professionals<br>Problem solving<br>Advocacy and information gathering<br>Changing relationships |
| | Finding a Place | Outside support<br>Changing relationships<br>Supportive professionals<br>Acceptance of visual impairment |
| | Societal Perceptions | Acceptance of visual impairment<br>Changing relationships<br>Locus of control<br>Positive outlook<br>Advocacy and information gathering<br>Outside support |

Table 4 continued

| Research Question | Category | Theme |
|---|---|---|
| | Uncertainty | Advocacy and information gathering<br>Self-care<br>Changing relationships<br>Positive outlook |

## Research Question 1

Risk factors are those pieces within a family's world that add stress and create the need to adapt and change to a new situation. Risk factors can play out differently based on a family and/or individual's background experience and the resources they have available to them to address the stressor. Research question one asked: What role do risk factors play in the experience of families of children with low vision? While each of the families in this study had a common risk factor of having a child with a visual impairment, Emily pointed out in her journal, "There are so many other struggles and concerns that impact decisions." While each family was different in the number and intensity of risk factors involved in their worlds, some common themes emerged from the data.

### Unsupportive Professionals

The presence of multiple professionals created a double-edged sword for the families in this study. While they all had professionals who had been incredibly helpful, all but one had stories of professionals who had impacted them negatively to such an extent they fundamentally changed the family's process and how they moved forward from the encounter. These professionals had the opportunity to provide relevant information to families and support them, especially directly after their child's diagnosis. Instead, the participants felt they either provided no support at all or input that was detrimental to the family's path forward. In some instances, as Emily put it, "I don't think necessarily that they haven't been supportive, I think the difficulty…is more the lack of knowledge.” In other cases, the conduct of professionals solidly placed barriers in the way for families as seen by Helen’s experience.

After Helen’s oldest daughter received her diagnosis of RP, she was sent in for further testing to determine how far her RP had progressed. Her five-year-old struggled with a test for night vision, requiring her to be strapped down with contact lenses with many different wires and things hanging off them placed in her eyes. After two and a half hours of trying, during which her daughter had vomited in terror, the professional “held her by her shoulders and said, ‘If you cannot handle this, I will put you to sleep and do it without your consent.’” When they chose not to continue the appointment and did not return for a follow up, the professionals turned them into Child Protective Services as they said they had no proof the family was caring correctly for their child. In the meantime, the family had found a different set of professionals to care for their child and had moved forward with services there. This led them to be hesitant to have their second daughter tested until she was older.

The first ophthalmologist for Ann’s daughter provided a challenge as well. From the very beginning, even her body language displayed pity for them and their daughter and implied it was a negative thing that she would have a visual impairment, ignoring the fact that the dad had the same visual impairment. Ann stated, “We just didn’t feel pity like that, or sadness, or you know, just really have that intense feeling about it.” They eventually moved on to a more positive and supportive provider.

Over the years, Grace has started to “just keep it generic” when talking with medical professionals about overall treatment plans for her daughter to combat the negativity she found within professionals. As a family, they decided to not talk about other areas of treatment with medical providers “because we don’t need the negativity or … their feedback for something they are not a specialty in…. We just talk about it with the actual experts in the field." Sarah ran into extreme negativity as well. The first eye doctor they were referred to "did not have very nice bedside manner. He talked a lot about what (our son) would not be able to do." As first-time parents dealing with a new visual diagnosis for their child, they found this to be very stressful so they switched doctors.

Mikayla had concerns about her child's vision at four months. However, the insurance she had at the time required her to go to a certain ophthalmologist who decided she only had amblyopia and therefore the insurance would not cover the electrophysiology test she needed to determine if there were other issues present as well. Instead, they insisted on patching (the covering of the stronger eye in order to strengthen the weaker eye), which only further limited her vision without any positive benefit. When her daughter was four, she was finally able to change insurance companies and therefore providers. They were able to complete the electrophysiology test and discovered the retinal issues that led, through genetic testing, to a diagnosis of Leber's congenital amaurosis. While her daughter was able to receive limited services for those four years, Mikayla felt "we were very delayed…we could have gotten a lot more resources if I would have possibly gotten other opinions." She came away from the experience feeling like she wanted others to know if "something is not right with your eyes, …getting another opinion like really just making sure that the diagnosis that you have (if it) doesn't seem right to kind of follow up and make sure you know it. Second opinions, third opinions don't hurt."

Sally encountered inflexible professionals in the early intervention system who felt as if certain services or techniques were necessary; however, they were unable to offer satisfactory explanations for why they wanted to deliver a certain therapy or test certain things. They were insistent about the path forward but could not provide the why behind the suggested interventions, which Sally stated, “Really rubbed me the wrong way.” The family went on to pursue different information and input seeking to make themselves the expert on their child.

Each family of a school-aged child had examples of different school professionals who had refused to follow through on the necessary accommodations to make their child successful in the classroom. Sally’s daughter was told her options during a ball activity in gym were “get hit in the face or sit out.” Helen’s older daughter had a teacher who “was basically like, ‘Yeah, I’m not gonna honor that’” when presented with the accommodations on her IEP along with another teacher who informed her that “accommodations are only a crutch and no one deserves them.” After an extended period of talking with different people, documentation, and problem solving, she was finally moved into different classrooms. Mikayla’s daughter encountered teachers in high school “that may not give her what she needed and she would have to go and ask for it to be in a format that would be something that she could use.” While she eventually had her needs met, it was not at the same time as her peers, delaying her ability to complete assignments at the same time as her peers.

Ann’s daughter had a TVI who refused to provide updates on her daughter’s progress, completed assessment without prior permission or notification, and unilaterally changed her access to written material from print and braille to print and print. Ann noted, “We were very aware that was illegal for her to do, so we addressed that. And her administrators made her change it back and then she was asked to not work with our child after that.” Sarah’s family was challenged by a TVI who did not provide the same level of service they had been used to from past TVIs: “He had had such a really good experience with the TVI in (the past) so when we moved here, we were underwhelmed with the support he was getting or not getting in some cases." There were multiple areas where she felt he should have been receiving instruction and was not, so she ended up following through on those areas herself after researching different techniques. As Evelyn has the same visual impairment as her son, it was important to her that he learn braille in case he lost more vision as time went on. The original TVI her son was assigned to came "up after a couple of years of trying, and basically says I give up. He can't learn braille because he can see." She was unwilling to present braille in a different way or to continue to try and teach him because she felt he still had too much vision to be successful.

### Trust

The unsupportive professionals encountered by participants undermined the trust they had in the system and stood in the way of a family's ability to gain the information necessary to move forward positively for their child. Ann laid out what was necessary to gain her trust. She required that professionals back up what they say with their actions by "showing me the things they say, and (she would) go back and verify that information…. So, I guess trust but verify." It was important to her that "everybody's doing what they say they're doing, and that they really do know what they are talking about." When trust was lacking for Ann, professionals had "shown with their behavior and their actions" that they did not deserve her trust and she felt compelled to "take action." Grace had a difficult time trusting that doctors and other medical professionals always had her daughter's best interest at heart or saw the entire picture of her daughter: "Sometimes doctors don't fully understand special needs alternative options, supports, and struggles."

Sarah has come to trust the IEP process more in some situations than the professionals involved in that process:

> In some cases, you're stuck with the TVI that's assigned to you so you don't always have the option (to trust). But we did definitely make sure that we expressed our concerns or you know our opinions and made sure that what we wanted was written into the IEP. So yeah, it's important to trust. You do want to trust the people who are serving your child, but you know that they don't necessarily always see things the same way and you just have to advocate. And we knew if it's in the IEP he's going to get it.

Regardless of how supportive families found professionals to be, they all struggled with trusting that their child's needs would be met in the larger world. Emily, who had had overall strong experiences with professionals, stated, "I just worry that once she is out in the world, she's not going to have the same type of supports. So, that worries me. It's ensuring that the people in her life and her circle are still there to support her, and that she can advocate for herself." Without the trust that the basic need for safety would be met, families found it difficult to move past that to believing higher level needs such as educational supports would be appropriately implemented either.

Helen worried that those around her girls would not have high expectations for them and would prevent them from reaching their potential through the limitations they imposed. She attended a presentation once on helping women with visual impairment where the presenter began with:

> These girls are never gonna wear makeup… and I was like, oh no, not for me, and I have done my make up without looking ever since. I don't know if my kids will want to wear makeup, but if they do, they will be able to and nobody is going to tell me that that is not a thing.

Sally had similar worries. When thinking about her daughter at school, she did not have "the confidence that when she enters into that environment she will be remembered. You know not even taken care of, but like she will be able to do all the things, even though she has needs." Sally's level of trust has changed over time. When her daughter first entered into school, she was attending an alternative school and Sally believed the team would "inherently notice, wonder, and adjust for her, and part of that came from the fact that they told me that they would." She stood back and watched the interaction until about second grade when "my trust shifted from trusting that they would know what do, to knowing pretty confidently that they wouldn't because of what I had seen." At that time, she initiated an IEP for her daughter and became more vocal within the school to ensure her daughter's needs were being fully met.

## Finding a Place

The families in this study had an innate need to find community and make connections with those around them. Sarah commented, "It is important for people to be connected to some sort of a community where they can share their hurts or their struggles, and there are people around them that will support them or walk alongside them." However, in general, they found it difficult to fit into their larger communities. They felt as if their child functioned too high for some situations and needed more support than other situations could provide. After attending a meeting for the National Federation for the Blind, Sarah left thinking "because he isn't as blind as a lot of them, I felt like we shouldn't be there." Grace's daughter struggled with spending time with others with less vision than herself as well and preferred to spend time with sighted peers: "Hanging around someone that … maybe has worse vision than her is somewhat, I don't know if it is overwhelming or if it's depressing, or if she just likes to feel 'normal.'" But at the same time, doing activities with her sighted peers was challenging due to her decreased vision.

Helen noticed that when trying to have her daughters integrate into activities with other kids with visual impairments: “Kids in particular feel their way is the best way. Right. Even if you explain to them but I can’t see the thing you see, or whatever it is, they’re like sure you can…Kids can sometimes be the least flexible with those kind of things.” Within a setting with sighted peers, the social pieces were what tended to be missed the most.

Sally commented that for her daughter, “One of the ways in which she was impacted early on, and I think it continues to have an impact on her social life is that there’s so much that happens in a public school setting that is beyond her field of vision,” which led to issues with forming and keeping friendships. Margie found the same thing with her daughter: “She never really had a close friend….And then having a para, you kind of wonder if that keeps kids from interacting…And she was never comfortable around kids of her own age…she was always happier to hang out with the adults.” Margie always wished her daughter could have formed more close friendships and was excited to see that she was slowly beginning to after graduation.

Parents struggled not only with their child fitting in but in finding support for themselves within the visually impaired community as there were such large differences in each child’s visual impairment and how families approached visual impairment. Helen felt that “when it comes to kind of special needs and stuff, people can be so judgy on the right way to do things or the wrong ways.” She has felt that judgment as a parent with how she chose to parent her children and felt her children faced the same things from some of their visually impaired peers as “we’ve chosen to handle this a lot differently than a lot of other people. Sometimes, when I do talk to other people, like sometimes we leave those situations feeling bad about ourselves.” Ann had similar experiences and felt that as a family they

> really had to find people that kind of have the same life philosophy that we did. But, a lot of parents would you know pity or have a different faith background, or have a different support system. So, we really avoid the learned helplessness piece of visual impairment and try to make (our daughter) do everything she should be able to do on her own as a 10-year-old, and probably even push her farther than that most of the time.

Ava had similar challenges when trying to fit into the support groups provided by the preschool for visually impaired children her son attended:

> My son is such an interesting case, because … he's blind, he has no left eye and super tunnel vision in his right, but he still has so much vision, right? Like he's just a different kid. You wouldn't know he is blind and he's always around these kids that have like medical issues or like are way more severe or aren't able to overcome those issues similar to (my son's). So, I've had a hard time figuring out where I fit in…. A lot of parents at (the preschool) are part of these mom tribes where they like go out to dinner or go on these like weekend vacations to decompress and be with other parents that are the same, and I think it's great and wonderful, and I probably could have benefited, but I never felt right being there.

Ventures into different support group environments left families feeling invalidated. Emily observed that

> it's been harder than I would have liked to try and find the community…some of the comments, it doesn't feel supportive, and it doesn't feel helpful. I recognize that not everyone has a beautiful journey of trying to figure out their visual impairment, but it is difficult when I am worried about trying to support my daughter, and then reading people

> being angry right? Which again, they have every right to feel. But, it doesn't feel as helpful on my end.

Mikayla mentioned, "Somebody who doesn't have a kid that has that, can't really understand what you go through with that." As Evelyn's family was so unique, she has been challenged to find another family to connect with. She felt that "we live in such a visual world" and due to her own visual impairment, "it's been a little bit harder for me to connect with other parents."

### Societal Perceptions

Set negative perspectives on visual impairment found within their communities and other families adversely influenced the families within this study. Those perceptions sometimes came from within their extended families or from others they encountered in the community. Sally summed it up well in saying "low vision seems to not be an understood entity in the wheelhouse of a lot of people in public."

Helen felt her family was "all so kind and supportive, but it can be one of the hardest parts. Sometimes there's the pity and that makes me tired….who feels great when they're just being pitied all the time? And I know that people are sorry we're in this situation, but that just never helps." Her mother-in-law "just wants to handle the situation" without stepping back and seeing what support would be the most beneficial. On the other hand, her stepmother "tried to tell my own kids that they'll never live alone…its' just like when she comes here, it throws her into her own grief about how sad this is." Fortunately, Helen has a large enough family that others are able to step up to help provide the balance. Her father "works a lot with the sick and the dying and all these things. So he's very used to like, let me be here until I see my role in this next thing…which is often managing his wife."

Ann encountered negative familial perceptions from her daughter's paternal grandparents. Even though their son has the same visual impairment, their cultural background makes the visual impairment "a shameful piece," which leads them to not "even like using the word blind or visually impaired." They push against any use of equipment or techniques such as braille reading or a long white cane that make the visual impairment more obvious. Sarah's brother told her right after her son was born,"you should probably never get pregnant again, because you know, you don't want to have another problem like this. (She) was really offended by that."

During the process to determine her daughter's diagnosis, after her first husband passed away, Mikayla faced push back from her former in-laws when she was seeking genetic testing. They felt like, "What do you mean this came from our side of the family? So that piece of it was hard for them, because it was not any direct correlation to them you know, I mean it just is. We can't control our genes right?" Though they did respond negatively initially, they ultimately accepted her daughter's visual impairment and moved forward. Emily's mother also struggled to accept her granddaughter's visual impairment: "that was really difficult for her to grasp, she was like 'oh she looks fine' I think, in her mind, she definitely thought of visual impairment as being 100% blind."

Ava's older son struggles with his brother's visual impairment. Her son with low vision gets "a lot of positive opportunities and (her older son) doesn't, so there's a lot of jealousy…. So, it's definitely, as they're getting a little older, changed a lot of the dynamic not necessarily for the better." They have had to work harder as a family to provide that balance for their children to bridge some of the gaps created by the inequity.

Reactions within the community created discord for participants as well. Margie's daughter struggled: "It's still hard when kids will stare, or will ask 'why are you in a wheelchair, why can't you walk?' So (we) try to empower her with the words to be able to explain the situation." Evelyn received many of the same reactions when they went out as a family. They often traveled together so they had one child in a wheelchair, one using a cane, herself holding onto the wheelchair, and dad or her sighted daughter pushing the chair. She was fine when people were curious or asked questions but

> I don't do the can I pray for your son, or can I pray for you thing. Yes, that's nice, you know I say thank you but no thank you. You could pray for me at church if you attend, that's fine, but God made me this way and He gave me the challenges, and I'm taking on this challenge.

Ann experienced issues when her daughter used her cane within the community:

> People are just weird. Sometimes I don't know how to say it nicer than that. But, they're just creepy and weird. They'll come up and touch her cane, or come up and touch her, or pray for her, and it's all very unwelcome. So, I think there's a lot of pity out there in the community, and I think it's just ignorance.

Although Mikayla's daughter is gifted and talented and highly capable, she repeatedly faced the assumption she was incapable of participating or completing activities because of her visual impairment. Helen's younger daughter experienced similar issues to the point that she "doesn't like talking about (her visual impairment) because it makes other people sad so she hates it."

Sarah found that having low vision and not always needing his cane could sometimes be more difficult for her son. While the cane provided identification of his visual impairment for those around him, without it

> he's probably bumping into people and plowing over people and they probably think he's being rude, and he's not being rude, he just doesn't see them. So, I think he's probably perceived in a negative way because they don't understand what he's not seeing, they assume he is visual.

Grace found the same to be true for her daughter. Regardless of whether she was using her cane, people in the community took notice of how she moved through the environment:

> Sometimes she'll use our arm instead of using her cane, she's slower, she runs into people. So, people definitely notice…. Her cane obviously brings out a lot of questions, head turns, looks, etc. It's definitely noticeable to people when we're in public just because she does need assistance even to guide her to the bathroom. I think it looks odd to people that I'm helping a grown size person to walk to the bathroom.

## Uncertainty

Facing uncertainty became a constant challenge for the majority of families within this study, especially when their child was given a diagnosis that included the potential for progression. Mikayla noted that "it does make you sad to think, you know my daughter, my kid, my child, might not see things when they're a certain age, or they might lose their eyesight." Sally pointed out that "there was just a lot of not knowing, and that can be an unsettling place." Grace found that "to be honest it was hard to even know when she got (her diagnosis) what that meant." Ava found that she and her husband had more "tears and venting time" after her son's diagnosis than before.

Helen went a little farther in describing what parents could go through by highlighting the process of dreaming for their child that parents naturally go through with a slight twist:

> What you learn is that you as the parent have created an entirely fictitious, but real to you, future for your kid. I like threw myself into like my child will never drive a car. My child's gonna need a cane someday, right? And you like, start going down this path of all these things. These awful things that are going to happen to you and then I realized, what if I had a completely sighted child that did not want to drive? My own brother hates driving and would love to go live in Seattle and just ride in trains and busses…. Like I made that whole thing up. I was grieving a thing that wasn't even real. Like, I was so sad my kid was never gonna drive a car. I don't even know if she was ever gonna want to.

The uncertainty continued to return even after the initial acceptance phase had passed. Margie experienced uncertainty again after her daughter's graduation:

> It's hard thinking about the future, about what happens as I get older, and making sure she is set up for independence. All that fun stuff. And so, a tricky time of wanting them to leave the nest, and then also being terrified of it and being able to do for her as she gets older.

Mikayla agreed, noting "you don't stop worrying about them when their off on their own." Ava found it difficult to always know the best way to help her son.: "You want to push them and can't, it's just kind of feeling out that balance of it all. There are definitely moments that I think it is harder." Sarah found that although her son had become very independent and she felt he was ready to move out on his own, she still stressed about certain pieces and not knowing how advancing technology would change things for him: "He is in the process of getting what they call biopic lenses ….  And he thinks, or hopes, that with those he might drive. I never want him to drive because I see what he misses." Although she wanted to support his dreams, she still had reservations about his safety.

## Research Question 2

Protective factors are produced by the combination of environmental and personality traits within a family that increases positive outcomes for that family. Every family’s experience of protective factors will be different based on the complex interplay of past experiences, personalities, current situations, and the complexity of risk factors present. Research question two asked: “What protective factors do families of children with low vision perceive to be most beneficial?” A group of protective factors emerged within this study to support the participants. Most of the factors were present for all families and one for just a couple; however, they all combined to create the overall high levels of resiliency experienced by these families. Protective factors were organized into the three different categories specified by Walsh’s family resiliency theory: (a) belief systems, (b) organizational processes, and (c) communication processes.

### Belief Systems

Walsh’s (2002) category of belief systems looks at how families are able to make meaning out of adversity, approach the world with a positive outlook, and hold different spiritual beliefs. Within this study, the common themes that fell into this category could be found in the families’ positive outlook on life, their acceptance of their child’s visual impairment, their locus of control when faced with difficult situations, and, for some, their reliance on their strong religious beliefs. The survey results showed this area had an average score across participants of 4.4 out of 5. With the exception of the question about religion, all other areas were either often or always a part of the family’s process. Religion always proved to be a part of the resilience process for the two families for which it played a role.

### *Positive Outlook*

All the participants in this study reported having an overall positive outlook on life and felt that even though they were realistic in recognizing the negatives and stressors in their worlds, they were able to look past those and find the positive in most every situation. Survey results showed that all families were almost always “confident and hopeful that (they) would overcome difficulties” and almost always or often sure their stressful situation was “common and understandable.” Evelyn noted, “We’ve tried to find the positives of course...there isn’t anything that stops us. We always figure out a way around it.” Mikayla stated, “It’s easier for us to find the positives in that situation. But I think sometimes the negatives become more apparent, you know, like it’s so easy for the negatives to kind of creep in, but we try to keep the positives.” Emily expanded on that, indicating her family:

> It’s pretty 50/50, and it’s funny because I almost feel like it alternates between (my husband) and I. We are both very anxious people, and so it’s easy to go down that rabbit hole. So, then the other supports with, okay, let’s look at all the positives, or even if these worst-case scenarios do happen, what could come of it? And so that’s why I say 50/50, because it’s almost like we take turns on who gets to freak out.

Sally pointed out that finding those positives could take some work on everyone’s part:

> You know, it’s 10 positives for every negative… we do a lot of talking about like what are you proud of that you found inside yourself in that situation, or what did you learn from it? And so, we acknowledge when things are hard, there’s a lot of validation, and also trying to figure out what was your learning point? So, just reflecting, reflecting back about the positives that could be found in a situation without like getting into toxic positivity.

Ann summed up what everyone else implied by saying that “it’s easy to jump into the negative, but we found that we don’t want to live in that kind of yuckiness.” She journaled that instead, they “choose as a family to work towards finding the positive in all things, to make the right choice even when it’s hard and to find a way to love on someone in tough situations instead of bombarding them with negativity.” In Sarah’s family, “some of us tend more toward the problem, but I think that more of us look at ways we can solve it. I think it’s more really solving and how can we do this.” Grace’s family utilized problem solving to turn negatives into positives as well.

Helen felt as if her family was almost too good at finding the positives. She and her older daughter did look for the positives in all situations but were realistic about the idea that the negatives did still exist. On the other hand, “My husband is actually bad at understanding the negatives at all. Like he just kind of assumes everyone else is also positive…I would say he and my youngest daughter are very much that way.” The participants found the positives within their situations did not take away the negatives; they simply mitigated the situation, allowing them to move forward in a positive direction.

Mikayla spoke about her daughter helping with their family’s positive attitude in relation to her visual impairment:

> (She) has such a funny sense of humor, and she actually brought a lot of levity to her own visual impairment. And so she would….make blind jokes, and I think it was okay for her to make blind jokes because she was blind…. So, I think it was refreshing as a family that we could all kind of laugh about it, not laugh at her, but laugh at times when she would do things.

Ann's family used humor to help mitigate stress as well. As a family, they worked to "find ways to joke about impractical solutions or find humor in some of our challenges all together. If we cannot laugh at ourselves, or a situation, then we lose sight of the important things in our life."

### ***Acceptance of Visual Impairment***

Positive thinking in each family led them to accept and even embrace their child's visual impairment. Survey results showed that to help with this, families often "focused on possibilities and trying to accept what they could not change." They reported almost always "sharing important values and a life purpose that allowed them to rise above difficulties."

Ann found her other children just accepted their sister and extended that acceptance to others:

> They've learned over time, I just need to let my sister get closer to things, or I need to let her do this, that, or whatever. And I have noticed that…if they see someone whose blind out in public, or they see somebody else with a disability that's very visible, they'll kind of acknowledge that in a different way than I think probably most kids do.

She herself felt her daughter was "born just the way God made her, and so she is who she is, and she wouldn't be herself without it." Her strong belief has allowed her daughter to accept her visual impairment as well: "Most of the time she doesn't think twice about it." She sees herself as "I'm a kid who has a visual impairment versus I'm a visual impairment and I'm also a kid." Ann journaled that in their family, they "choose to look at disabilities as part of a person but not something that defines that person in our family. Regardless if we have a label or not, everyone in our family has different strengths and weaknesses." Ava felt the same. Her son's "visual impairment is just kind of who he is." Grace was younger when she had her daughter and she remembers thinking that "it's your child. So, you just had to do what we had to do…you just have to adjust your parenting. We didn't really question that. We just did what we needed to do to make her life easier." In Evelyn's family, as visual impairment is such a prevalent part of the family, it is seen as a smaller piece of who they are:

> I think we're each our individual person. Each of us has our own personality. Each of us at times has our own hurdles that we have to overcome, and other family members help with problem solving whether it be creative or just a shoulder to cry on and an ear to listen.

Emily found her daughter's visual impairment had "not stopped her. Sometimes I wish it would stop her just a little, but she compensates so well." She went on to say that her daughter did all the same things as her brother, just in a different way. Sally felt her daughter's impairment "is what it is. I want to make sure that she's empowered to advocate for herself, and that she can access the world with the least amount of friction as possible."

Sarah journaled that within her family, they "don't use vision as an excuse, don't impose limitations but instead let the child determine/discover his or her own limitations after they try things out, and talk about what CAN be done, more than what CANNOT be done. Never say 'can't'!" Initially after her son's diagnosis, she found it difficult to see the positive way forward for him; however,

> now he's going to the University of Massachusetts in Lowell…I'm really excited about it. I know I'm going to miss him, but I'm really excited for him, because I really feel like he's ready to fly and really test his wings… I never thought I would be at this spot, but I am at this spot.

Margie felt similar to Ann and accepted her daughter's visual impairment as just a part of who she is. She felt "we were kind of prepared because they were preemies and twins, that there would be some additional challenge…and also being first-time parents, you just don't know. So, you just make do with what you have and try to maximize the opportunities." Their extended family had experience working with individuals with disabilities so both she and her husband had been exposed to that throughout their lives. Those experiences made it easier to absorb the new experiences of visual impairment even if they were not directly related to visual impairment.

Mikayla's and Helen's daughters were a little older and they both had strong feelings about how their children's visual impairments had formed them into the young ladies they are today. Mikayla expressed: "She is who she is because of her vision. She's grown up to be who she is, because of the resilience and what she's had to overcome and to learn. And she wouldn't be who she was, you know she would be a different (child)…. which would be sad."

Helen felt very similarly:

> I'm thankful for the perspective it's given them that's made them them. You know, like they're so understanding of other people's hard things and stuff like that. And that's the thing that takes people so long to learn. And so I'm thankful they have that and I don't want to wish away who they are…. They've got like beautiful brains and I don't want anything to change that.

She went on to state, "Life's hard, you know, that's gonna be true, I can't make that not true," but she strongly felt that moving forward from those difficult experiences positively was well worth the effort.

### *Locus of Control*

Every family in this study felt they remained in control of their own choices and in the difficult situations they found themselves. Their survey responses indicated they almost always "approached a crisis as a challenge they can manage and master with shared effort" and they "made sense of stressful situations and focused on their options."

None of the families felt like the visual impairment had control over their family; rather, they felt like they controlled the visual impairment. Ann specified that she "controlled the visual impairment for sure. I control how I can react to the visual impairment is probably more how I would say that." Sarah thought along the same lines:

> I think we control it….because I think we don't give it the power to stop him, you know, or to get in his way, to keep him from doing things that he wants to do. We don't give it the power, you know, to use it as an excuse for anything. So, I would say we don't give it the power. We have the power over it.

Sally emphatically felt it definitely did not control their family. She indicated they "have very consciously identified areas where it has impacted them in the past and then made modifications to our family prototype so that we don't keep rubbing up against that same friction point." Helen's family "pretty much decides what we want to do, and we don't like forget that" the visual impairment is there; they just move forward embracing it and their daughter's differences "that's part of the lens of honoring who they are." Margie and her family "seek out opportunities where it's a non-issue" as much as possible or put into place the supports necessary to allow them to move forward successfully. This was very similar for Grace and her family. Grace recognized that the visual impairment was becoming more impactful for her daughter as she lost her vision but simply problem-solved through it in each new situation. For Evelyn, "I was brought up to believe that can't isn't a word. That unless you try, you will never know if you can." No matter what challenge was placed in front of their family, they found a way to move forward through it. Ava agreed, stating that in their family they strongly felt they could "control it, I would say that it doesn't control us."

Other families felt that when their children were younger, the visual impairment might have taken up more time and energy but even then, they felt an internal locus of control. Mikayla communicated, "I don't think that it controls us. When she was littler there was a lot more pieces….so I think that when they are younger you do tend to, you know, have it not so much in control, but be more of a focus." As her daughter grew, it faded more into the background. Emily felt that "initially it was, it felt like it was taking over us. But I think once we got the foundation down, now … it's definitely manageable." This feeling of being in control of their own situations could be seen across the interviews and the journal responses in how they gained information and dealt with the various professionals the visual impairment brought into their worlds. Others implied what Sally summed up well in saying, we figured

> out what is in our control and what is not in our control by figuring out what options we might have by, you know, using our strong voice and advocating for ourselves, and by understanding that we don't have control over everything, and sometimes things don't work out the way we want them to, and then what are our options? We talk a lot in our family about the only thing you can control is, you know, yourself.

### ***Religion***

Religion was a factor for only five participants; however, for those families, it was one of the primary resources they listed as being the most beneficial for them. They found support for assigning meaning to their child's visual impairment, looked for community support within their faith communities, and found support through feeling their prayers were answered. Mikayla's family goals when her children were younger centered around raising "our girls up to know who

Jesus is, and to have a relationship with Him, and to love Jesus and to help others, you know care for others." She continued by saying "We had a lot of spiritual support, like our church family, like we were very involved in our church, especially when our kids were little." Their pastor, the church family, and other church families who had small children were the bulk of the support system she had when her daughters were growing up.

Ann's family was "very much a faith-based family, so we believe that this is how God made her, and that's just who she is so we were able to really rely on the faith piece of that to get through (the diagnosis) for ourselves." Her family supported themselves through challenging situations by thinking "what would God have us do here. We're certainly not perfect at that by any means, but we rely a lot on our extended community at church." Within that church community, they have "small groups that we participate in, and we go to them and we pray about things, and they pray for us, and we have those people that we can kind of talk to, and just really walk through: how are we going to handle this the way our faith would have us do?" Ann felt strongly that "without faith, we just wouldn't have that center to pull from, we would kind of be lost at how to handle situations and how to manage some of those really overwhelming, I don't know what I'm gonna do tomorrow with everything, kind of situations."

Grace's family relied heavily on God as well: "We're Christian so we do a lot of praying… We rely on God for support." Throughout the uncertainty of her daughter's diagnosis, "we just have to lean on prayer a lot." Evelyn felt that in the past she had not been "a strong believer in God, but with my complicated pregnancy, I have to say that there's some higher power the showed me that everything was going to be OK, and part of me falls back on my belief of God and he's helped to guide us." Sarah's belief in God allowed her to believe that

> God has a hand in this somehow. And believing that we see things differently than what God sees things, and you know it's not a punishment. It's something different, and he's going to have unique qualities, unique characteristics, and unique abilities despite that, or even because of that, actually, probably because of that quite frankly.

This strong belief allowed her to move forward even though it was difficult for her to initially see anything but the negatives in her son's diagnosis.

## Organizational Processes

Walsh's category of organization processes looks at how flexible a family is, their connectedness with those around them, and their ability to mobilize social and economic resources. Study participants found areas of strength within this category when looking at their information gathering and advocacy skills, the support they found outside of their immediate family, the supportive professionals who entered their world, and the use of technology for education and furthering connections. The survey results from the six participants showed an average of 4.4 in organizational processes.

### *Advocacy and Information Gathering*

All of the families within the study felt they had to become fierce advocates for their children and as a part of that, they had to seek out the information that allowed them to move forward as an expert on their child's visual impairment. This matched the data from the survey, which indicated that every family almost always "believed they could become stronger from their challenges." Grace commented that "just having knowledge was probably a key game changer." Emily noted when reflecting on the importance of research that "as soon as I hear something… I have googled it 14 times and gone down different rabbit holes, and I have an Excel spreadsheet." In her journal, she went on to say that it was important to "research possible options and solutions as well as what impacts these decisions could carry.” Ann and her husband are

> both information gatherers. So, I think one thing that helps settle us is … if there is something that’s going wrong in a situation, or we want to change how it is going, then we just kind of both pour ourselves into that situation. We’ll find out as much information as we can, so I think it’s that grasp of control trying to be able to figure it out if there is a way we can control some of this.

Sarah and her family did “a lot of research and then at mealtimes, we take turns leading the dinner table conversation.” They were especially interested in different technology and medical advancements that could play a role for their son such as gene editing and self-driving cars: “We’ve tried to stay on the front end of things like that.” When her son was first diagnosed, Sarah’s research looked a little different; they “went about doing things so that they could make sure he had what he needed. We didn’t just rely solely on the TVI, we did what we could to research and investigate what options there might be for him.” She spent time looking for different organizations or people who could provide the information she needed to best help her son be successful while not living in the United States. When he was in high school, their research took yet another turn. When they did not agree with the direction her son’s TVI was going, “we made sure that we did the research. We knew that what we were presenting was research based, you know, scientifically best for the situation.” In that way, they were able to argue to have what they felt their son needed to be placed onto his IEP.

Sally combated the uncertainty she felt with her daughter’s initial diagnosis by surrounding herself with resources and knowledgeable professionals and Makayla journaled about how “educating yourself when you receive the diagnosis is very important so you know how to best help your child.” Helen approached the initial diagnosis by determining “we were gonna find the people, we were gonna ask the questions…we got the medical textbooks, we read them, we did not get some little ’How I go shopping as a blind person’” pamphlet. They were determined to learn as much as they could about their child’s visual impairment and the pieces surrounding it.

Ava had a similar approach. She and her husband recognized early on that they did not have all the answers and that to gain those answers most effectively, they would need to combine different skill sets. They immediately went to “who do we need to call, oh, Aunt… you’re in the vison world, what do you recommend. We’ll find the resources we need.” As their son got older, they continued along that route by pulling in different family members and professionals as they went to help with areas where they were less certain. For example, when they were having issues with getting insurance to cover things like their son’s prosthetic eye,

> my mother-in-law got involved, because that’s where her skills are, her job is like doing billing and insurance. So, when he was younger, we had her do all of our phone calls fighting insurance. She knew exactly what to say but I would have never been able to do that on my own.

Makayla and her husband “learned how to read braille and write it…we wanted to learn as much as we could so that if she did go blind, we would be able to help.” Ann pushed to learn all she could to understand what her daughter was doing in school as well: “I want to be able to have access to everything she is doing and to be able to support in everything that she is doing, that was a really big piece for me.” Both Ann and Emily chose to become TVIs after their daughter’s diagnosis to gain as much knowledge as possible.

Sometimes the quest for knowledge became one of the greatest hurdles families faced. Helen consistently ran up against professionals who either had no information to share or shared in a way that was not beneficial for their family. This drove them to adopt the mantra, “We are the experts of our own child.” As they were told again and again there was nothing they could do about their children’s visual impairment, the family decided:

> If that is how they choose to feel about it, we are the ones who will have to do something about it. So, it changed our whole mindset from being in an aspect of like we need to seek out help, we need to find the people who are going to help us be what’s best for our kids, to, we are those people and other people can come ask us what they can do to help with our kids.

As a result, they carried out their own research and surrounded themselves with a specifically selected group of professionals who would help them to problem-solv new situations and provide support in a way they believed in as a family.

All the families in the study felt empowered to advocate for their child and what was best for them even if that had not been an area of strength in the past. Evelyn talked about how she used to approach advocacy before having children versus how she does now.

> Before I was very quiet and a push over. If I went to the doctor and told the doctor I was there to be seen because of heavy migraine headaches and the doctor said, well, if we cut off your right arm then the migraines would go away, I would say, Okay. When do I go to surgery? I wouldn’t ask any questions, doctors knew it all. Now I’ve completely changed. There is nothing that I don’t ask. I do my research. If I don’t understand, I’ll continue to ask until I understand.

Sally emphasized the importance of

> establishing the relationships between myself and those supports such that I either know the right questions to ask or can advocate for her, not in a helicopter way…. (but) I guess just the relational piece of feeling confident and like I have the relationship with people to be able to problem-solv on behalf of my kiddo.

Helen voiced, "I feel like I became the fierce leader in the situation (even though) I didn't necessarily go there to become a fierce leader." Every school aged family felt they had had opportunities to advocate within the school setting to have their child's needs better met. Sarah's comment captured the essence of every participant when she said, "I think it was important for us to make sure that he had an equal access. You know, that he had equal opportunity that he wouldn't miss any information just because he had a vision impairment." This took on many different forms from needing to advocate for inclusion within classes such as gym, full implementation of accommodations to provide access to school work, or advocating for the correct pieces to be put in place to ensure their child's safety in a new environment. Grace found, like others, that changing between different grade levels could be problematic, especially the transition between preschool and kindergarten. She felt that in preschool,

> they had really set her up to be successful, had all this documentation about…this is what works with her, what doesn't, and then when she went to elementary school and the teachers were not equipped to deal with kiddos like her and the situation got worse…. We had to advocate for her and to get other people involved to make the situation better.

Ann commented that their advocacy sometimes happened behind the scenes without her daughter's knowledge:

> (My daughter) doesn't realize it, but there's a lot of stuff behind the scenes that goes on if I can't trust you and you're showing me that with your behavior and your actions as one of the professionals, I take action. She has no idea again that most of that is ever going on. We address it with the principal or whomever the authority figure is.

All of the participants worked hard to pass on their advocacy skills to their children so they would be able to advocate for themselves as well. Most all of the families, when presented with day-to-day challenges in school, approached it the same as Sarah had with her son: "We've tried to make sure he is the one that's approaching that" with the teachers and they supported from behind the scenes.

Helen put a different spin on the information gathering she and her husband did. She acknowledged that half of the driving force behind it dealt with her need to become an expert on her children as she was unable to find other experts. The other half of her motivation was:

> It is just how we choose to parent in general. Like it is how we always wanted to be parents…it's the way we want to show our children their value. You know, it is that they will always be our absolute largest investment and priority. So, part of it doesn't have to do with their visual impairment at all.

### ***Outside Support***

Outside support can look like many different things for each family. The survey results showed that families felt often within their "immediate and extended family, (they) had positive role models and mentors" and they could often "count on family members to help each other in difficulty." Participants found support from extended family as well as carefully chosen community support to be invaluable as they negotiated the new world of visual impairment.

All the families within the study had sought out opportunities for their children to make connections with other children with visual impairments or other disabilities. Margie involved her daughter in at least five different groups over the years and felt they allowed her to “meet new friends who they had something in common with and to be a part of something bigger and expand their life experiences and independence.” Ann felt activities with others with visual impairments allowed her daughter to make connections because with

> all the different types of visual impairment that there are, she can find kiddos who have better vision than her, worse vision than her, and those who are completely blind. So, she really gets to experience all those different aspects and doesn’t feel so different anymore.

Three of the families sent their children to Foresight Adventure Guides for the Blind, an organization that provides ski and other outdoor adventures for children with visual impairments. Sally felt that at Foresight, “It is not like a stand-alone that she needs this (accommodation), and people have to remember it, and then she has to get special services. It’s like everybody gets this.” She felt it was “the biggest connection for us, that opportunity to connect with other kids who are similarly visually impaired.” Ava found Foresight provided “a little community within that that has been really helpful, just kind of another place to go for his self-esteem and things to do.” Helen also found value in that experience and used it partly as an opportunity to

> help them know how involved they want to be in the blind community…. I don’t feel like it is my choice to decide that she doesn’t have anything to do with the general public anymore…there’s tons of things you can do to be mostly around other visually impaired people...but I can’t make that choice for them.

Mikayla’s “TVIs and the mobility specialists, they did a great job of bringing families together” so they were able to establish a connection within their home district. Part of growing up, especially during adolescence, is finding your place in the world and making connections between yourself and the peers around you. Having peers who had a visual impairment similar to theirs allowed the children within this study to not feel as different and to find a place where they did not have to continually explain themselves or feel scrutinized or judged by others. Emily found solid connections for her and her daughter within her “early intervention family”—those professionals and friends she worked with.

While the parents felt like connecting with others with visual impairments was a positive for their child, most did not feel the same for themselves. As Helen put it, “Sometimes we leave those situations feeling (interacting with other families) bad about ourselves, because we still make our kids go to public school, or whatever the thing is.” Sarah was the only participant who found the right combination of other parents of kids with low vision when her son was in preschool and remained in touch with them as her son got older. She was “able to share our experiences and garner ideas from each other.”

Instead, almost every parent felt as if they made the best connections with other adults who had had hard things happen with their child no matter the cause. Helen stated, “When you talk to parents whose kids have never really met any challenges of any kind, they sound just flippant…it was still easier to sit and talk to someone who knew about like hard things happening to your kids.” Emily found the same thing within her family. She was able to make the most connections with her siblings who “have had their own (hard) experiences and so I think because of that they can empathize with our experiences, and they draw from how they were with their own kids to support (us).” For families within this study, finding other people who understood adversity and supported parenting decisions made more of a difference than having someone understand the visual impairment.

The outside support participants found came from various sources including other parents, professionals, family, and friends. Helen pointed out that the help did not always come from "the people that you would have expected. Yeah, ironically, (support came from) usually other parents who had hard things with kids, and for other people that was too hard and yucky to have to touch." Emily journaled about not having a lot of connections with other families of children with visual impairments; however, "we have met families whose children also have diagnoses. Although it is not the same, it is nice to be able to discuss (and commiserate) about numerous appointments, shared therapists, looking at school options, etc. with other parents who understand." Margie also journaled about finding "Darling Doubles a mothers of multiples club, which despite having nothing to do with (her daughter's) disability or visual impairment, proved a lifeline and tremendous support and friendship that I would not have survived the early years of parenting twins without." Grace found the same thing: "When we first got the diagnosis, we didn't really know what it meant and how it was going to change our lives." However, she and her husband were able to find support from "other families that have kids with disabilities."

Ava really valued the organizations she found that would help provide support for not only her son with low vision but his older brother as well. One of the most beneficial organizations she found was the Stink Bug Project that trained dogs to be given as companions, not service dogs, and now her sons "have joy in their lives." Through Stink Bug, they have made connections with many other organizations and opportunities.

Ann sought out support and reassurance from adult friends who had visual impairments as well as her daughter's father:

> He's successful and he can do what he needs to do so I think that it helps a lot to be able to see him. I also have some adult friends who are blind, who I have actually known since

> before I had (my daughter). So, I really lean on them as that piece of hey, this is going to be okay. You know, we talked through a lot of things when she was younger about like: How is she gonna do this? How did you do this? What was your experience with your peers?

Those adults with visual impairments became mentors for Ann and her family.

Sarah found invaluable support from a renter they had at the time of her son's birth who was visually impaired. When she first started talking more with her renter,

> I was a lot more focused on what he would never be able to do, and he would never be able to see this, and he would never to able to…and I would go to visit her once a week with (my son) and she actually helped me to see what people are capable of…and she just taught me all of these things… and I really believe it was a really miraculous opportunity for me… I wished every parent with a baby with a visual impairment could have an adult legally blind person mentor them because I felt like I got this free mentoring…that was an opportunity for me that really changed my perspective and my expectations. I just got to see what abilities they have, not disabilities.

Every family within the study found positive support from their extended families even if they did not live close by. Mikayla felt her extended family treated her daughter "just like the other kids. I think that at times because (she) would over compensate for things, they would forget that she had a visual impairment." Helen felt that in her family, "everyone is super involved and accepting…we have so much family and they're all so kind and so supportive." Although she sometimes struggled with the different types of support each of her family members provided, she valued their presence and support. Sally noted that her extended family "are mostly just curious, and try to be mindful." For Margie, her extended family was a tremendous support and provided childcare, respite care, and financial support. She journaled that "it was sometimes hard to ask for or accept help, but we could not have done any of it without the help and support of others … it truly takes a village." Ann felt "our extended family is really key for us." Her parents did not live close by but came to "visit a couple of times a year and we talk a lot and have facetime and that sort of thing with our family." Her in-laws lived close by and without them, "we'd be lost."

### *Supportive Professionals*

While every family verbalized times when they struggled more with the support they received from professionals, they all had an equal number of opportunities for positive interactions as well. Survey results revealed all families almost always could "rely on the support of friends and their community" and often felt they could "access community resources to help (their) family through difficult times." Evelyn utilized a strategy that was somewhat universal when she sat down with each new provider and made "sure that they're willing to be a part of the team and work with other doctors" before agreeing to allow them to work with her child.

Sally asserted that providers sharing resources "has continued to be, I think, my biggest source of support, and the hope and positivity is the providers who have been knowledgeable and sharing the information they have." At times, those professionals might only enter their world for a short time but still provided a lasting impact. Sally quickly developed trust in the professionals at a low vision clinic her daughter attended where they presented multiple different technologies and really looked at each to see "what she's getting out of it, and then let's determine if this is a functional tool for her, if this has function and support for her." She found huge value in having professionals really listen to what she and her daughter were saying and strive to match their support to what was most needed. Sarah found the same positive support through the low vision clinic: “Dr. …, he’s been an invaluable resource, too, we’ve talked to him a couple of times here and there about, we’re looking for this, and what ideas do you have for this. So that’s been a really good resource.” Grace found the same to be true of the professionals she found in the school system. The “schools have been very impactful, with what she’s learned and what we’ve learned at each level of schooling…. A lot of what we’ve learned is coming from the support from the schools, paras, or teachers, and the vision assistance.”

The child’s TVI and, if they had one, orientation and mobility specialist were universally solid supports for families. Mikayla stated that “those individuals really, really connected with me, you know, like I would ask them questions and they were really good about pointing me in the right direction to get resources.” She felt that while she actively sought information and resources about her daughter’s vision and felt a need to become an expert about the visual impairment in the medical realm, she did not feel the same need within the educational environment: “As far as her professionals that were working with her more closely on a more daily basis, I didn’t need to be an expert on that…I couldn’t be the expert only because they were already helping her so much more than I could.” Ava felt much the same: “His teachers (at school) have been phenomenal….He’s had wonderful teachers and the same TVI since kindergarten so she really knows him, which has been great.” She felt strongly that “they have been a little community for us, I know if I ever have questions, I could always reach out…which has been phenomenal for us.”

Emily shared in her journal:

> Early intervention (EI) was a huge support in the start of our journey. Having an EI-TVI was vital to gathering and understanding information. She also helped support us when we were overwhelmed or scared of possible outcomes there may be for our child.

> Inevitably, there is a lot of jargon that is involved with any diagnosis, so it was helpful to have our TVI lift the veil on reports that we received.

Helen had worked hard to “have a good relationship with her case manager at the school level and her vision specialist, so I can delegate to them, and put that on their plate for them” to ensure her daughter’s needs were being met at school. Other beneficial professionals included related service providers such as speech therapists, occupational therapists, and physical therapists, pediatricians, and eye care professionals such as ophthalmologists. For Margie, part of building that trust was refusing bus service for her daughter “because I liked having that contact with the teacher, with the para at the end of the day and I knew I would lose that if she took the bus…there is a level of just wanting to keep communication with the school.”

Ann had worked hard to develop a strong relationship with her daughter’s TVI so she was able to “accept I’m (my daughter’s) mom, I’m not (her) TVI, so I have really made a point to set that boundary.” She would offer her opinion when asked but was able to trust in her TVI’s process. She found her daughter’s case manager to be “phenomenal.” Even though she did not have direct time with her, she “just goes in to make sure that accommodations are being met in the classroom, making sure that she’s able to step in when her TVI is not there to support the classroom teacher. She has absolutely gained my trust.”

Even Helen, who had some of the most stressful interactions with professionals, had landed in a place where she felt supported. She found an “ophthalmologist and retinologist… they’re so kind and helpful…(even though) some of it has been like experimenting together.” She felt her daughter’s TVI had “been amazing in all those things. She’s very very cool with listening to all those things” that are important to their family. Their relationship has developed to the point that she feels comfortable trusting she will advocate for her children as well and has developed a tag team situation where sometimes the TVI advocates first and sometimes she does. The orientation and mobility specialist has been equally supportive and Helen believes she would “make things happen” for her girls as well.

Mikayla attributed her daughter’s positive adjustment to the professionals in her world: “She adapted very well because she was able to get the services she needed right away… I think if she would have had to wait till she was older, she would have had a lot more struggles.” She went on to say, “The consistence of people throughout her schooling has been huge to our family.”

Six of the participants spoke about having some type of counselor involved with either themselves or their families helping them to work through what they needed to emotionally. Two of Ann’s four children have counselors they see regularly and her daughter who is visually impaired initiated beginning therapy on her own. Ann tried to ensure her family “makes sure they prioritize their mental health as they would if like, oh my throat hurts, or you know I have a headache.” She and her husband model that by prioritizing their own mental health as well.

### ***Technology***

Technology often became a tool that united families to the support they needed most. As many of the participants’ extended families lived farther away, technology was able to bring them together. Emily and her family “try weekly to have a video chat altogether to catch up.” Margie noted her family’s response to accomplishments is “a lot of texting. And then just kind of group support…sharing of videos of things that have happened or pictures, and then family is just kind of responding and showing their excitement and enthusiasm.” Ann’s nuclear family lived away from the support system her extended family provided so “we face time a lot so that they can see the kids and the kids can see them,” allowing them to be brought closer together.

Emily indicated in her journal "I had our daughter during the pandemic, so we were unable to meet with other families." And yet, "it was also important for us to find a mutual community…(so) we found some Facebook groups and joined NOAH (National Organization for Albinism and Hypopigmentation)." While Helen found support in online spaces, she did speak about needing to find a way to control all the information coming in. When her daughter was first diagnosed, she

> immediately looked for support groups online, like Facebook groups and you know social media options. Because again, it being such a rare diagnosis, I don't know, anyone else who has this. So, you look to those things you have available to you and some of that I think is fantastic and some of it's not… At first I would just sit there and I would look, I'd read all the chat rooms all those things just trying to learn, learn, learn, and then I learned I had to mute that so I never saw that unless I was choosing that.

This prevented her from becoming too overwhelmed by all the emotions involved within the chat groups. All families have found mixed results in online groups but mentioned in their journals that there was value in making that connection. Families within this study all developed a concept of what supports would benefit them the most and made choices allowing them to increase access to positive supports and decrease exposure to less positive supports.

All families spoke of using the internet as an information source to gain more knowledge of their child's visual impairment. Sarah and her family moved back overseas soon after her son was born and she used the internet to remain connected with the early intervention program she started with here in Colorado as well as to complete parent educational modules from the Hadley School for the Blind. This allowed her to continue educating herself on how to best support her son without having to be close to the support system. When Helen was unable to gain any input from the professionals she went to, she and her husband chose to gain all the information she could from the internet. She found some of the best information in the unlikely form of YouTube videos created by individuals with visual impairments: “Just to watch them live happy lives was probably one of the most handy things honestly.” Grace made use of YouTube videos as well as she went there for “tips and tricks, and what you should do and shouldn’t do.”

One of the largest supports all families found in technology was the independence and access it afforded their children. It allowed them access to materials both near and in the distance that they would otherwise have missed. Ann’s daughter

> has most of her books on an iPad, she has a CCTV that magnifies her materials at home when she needs to, or a handheld magnifier which she prefers to use to read in bed. And so she just kind of figures out what works best in every situation. She carries a purse around that has all her tools in it like her monocular, her magnifier, and her reading glasses.

Within their home, “it’s just really a normal thing…it’s not something we are overt about…it’s a very normal thing in our household.” Evelyn made use of the same types of technology for herself so she was able to compensate for her visual impairment while parenting her children. She uses, and teaches her son to use, different apps to visually identify and read things in the environment, for GPS services, to access things on the computer, and to complete research.

## Communication Processes

Walsh’s (2002) communication processes explored the clarity with which a family communicates, how open they are with sharing emotions, and how collaboratively they problem-solv. Common areas of strength within this process were found in the goals families set for themselves, how relationships changed to meet new needs, their ability to communicate with each other, the need for good self-care, and how they approached problem solving. The survey results showed an average of 4.3 in communication processes.

### ***Goal Setting***

Survey results in this area pointed to families often or almost always using goals to "plan and prepare for the future and try to prevent crises" and "focusing on (their) goals to take steps to reach them." Every family set goals as a family that revolved around increasing their connectedness as a family. Mikayla and her family had the goal of "really staying in a close-knit family as they're growing older…continually trying to go on family vacations together, and to do things together and to be around each other." Emily's family goal was similar: "We really want to have quality time together. That's a big goal for us. We try to focus more on experiences rather than like physical items." Margie's family strove to "figure out how to meet everybody's needs and still fit in travel and fun time for us." Ann's family "works on building times with each of the kids or have specific activities each week we do for the kids as a way to connect." Ava and her family wanted to "raise good people and keep everybody happy."

Sarah and her family place great value on family connectedness and as her son has just graduated from high school, she is hopeful that both he and his sister "would carry that forward into their own lives when they become independent. Ideally, they would understand the importance of valuing the richness of sitting down and having, you know, conversation and community at home." Grace's family strove to maintain connectedness as well with an emphasis on "helping each other as needed," ensuring that everyone "has an opportunity to speak for themselves rather than being spoken for," and making sure they are constantly keeping in mind each other's needs.

Helen and Sally approached goal setting in somewhat similar ways. They both looked at it as a continuous process. Helen and her family "always just want to set the next goal. Like we always try and have a thing in mind like as a couple and then as a family, and then for our kids specifically." Currently, their goal is to plan family vacations that focus on the interests and uniqueness of each girl. Sally and her family have goal setting conferences each Sunday when they are together where they talk about what is important for each person every week. Overall, they "love to travel, we like to challenge ourselves outdoors, so we do like every summer, every major break, we do a bucket list of things we want to accomplish over that break, and then we try to make sure that those things happen."

### *Changing Relationships*

Almost every family spoke about the need to really look at how they interacted as a family and make changes that would allow them to move forward in a more positive way after their child's diagnosis. Survey results emphasized families' need to often "show each other understanding and avoid blame" and the ability to "express our opinions and be truthful with each other." Helen shared:

> We had little kids. We were working hard and we were like, we'll have time for a cool marriage later. What's up business partner, and like you know, high five tag out. It's like we were doing business. Making it work. And then we had to stop and be like we need each other right now. You know, like he changed, like got a different role in his company and we had to like make moves to make sure we could at least be there for each other and them as much as possible.

She now felt it was imperative to constantly work on their relationship because you never know what may happen next.

Emily found the need to change how she related to her husband as well. They have found the need to take a step back and provide "reminders that we're on the same team, and we're trying to figure out the same thing together, and we will figure out the same thing together, it just takes different ways." She felt that while "it's definitely been a journey to get there, I feel like we've finally gotten there." She, like other families, had a heightened sense of accomplishment in having acquired a new way of communicating or relating within their family. Margie journaled that she and her husband had to very quickly make changes to their relationship to make it stronger as they had the twins very shortly after getting married and only 10 weeks after they discovered they were having twins.

Ann has had to work at balancing the relationships between her family and that of her daughter's father in order to move forward positively. As a group,

> we actually all get together on the phone often, or we have like a group parent text so we will all talk through things together all four of us…. I would say we have to be really intentional and positive about our communication because it's really easy for us to just get in there I guess and blame each other. So, we've been intentional, intentional is definitely the right word for that.

Ann and her husband made changes not only in how they communicated with the other adults in their world but in how they worked to support each other in parenting decisions as well:

> We'll take a step back when the kids aren't around and really reflecting on our reactions to things, like was that my emotional reaction? Was that the best strategy that I use for them? Is that how we're supposed to be reacting to that? Are we self-reflecting as parents? And I think that's probably the one thing we talk about the most together. It's

> really important to be able to self-reflect and to help each other. To say hey, I think next time you probably need to handle it this way. What do you think about that?

Ann felt that making these changes to their parenting style helped them draw closer together as a couple as well as improving their ability to parent within a blended family situation.

Sarah found that as a couple they needed to work at finding a balance in their expectations:

> I tended to be more protective, and my husband tended to be more pushing him. So, I think we actually balanced each other out pretty well and it ended up benefiting our son…. I often thought if I raised him by myself maybe he wouldn't be doing as much as he is. Of course, there were times where I thought, oh my God, you are going to kill him!

They had conversations as well about making sure to not minimize the challenges faced by their son and acknowledging the pieces that were different for him. When Grace thought about how she and her husband approached parenting their daughter, "surprisingly we were really on the same page when it came to all that." The change for them came with how they balanced things with their other daughter and her understanding of how to interact with her sister.

Ava and her husband are working to find the balance between what they each did for the family and making sure they are consistently reading each other's nonverbal cues:

> I think part of our challenge is that we look at things differently, and being a married unit you kind of have to be on the same team. If you're not on the same team it doesn't always go right because then the kids have inconsistency. So, I think a challenge for us is getting up to be on that same team, to not just say we are on the same team.

She felt there were often times when they would say they agreed with each other to move on but "I don't believe it in my bones." Changing to find that place of more complete agreement has been a journey for them.

The new relationships being formed were not always within the family. Helen felt that after her girls' diagnosis, her friendships changed as well: "Some of the people I thought that would always be there for me, rock solid like, were 'peace out' and other people were like, 'I got you, I am here' so they weren't always the people that you would have expected." For participating families, getting to the point where they are able to have open honest relationships that allow them to support each other through challenging situations took hard work and determination.

### *Communication*

Survey results indicated that families valued highly open and honest communication. They were often "clear and concise in what (they) say and do," expressed their "opinions and (are) truthful with each other," and they could share both positive and negative feelings with each other. Along with that, they felt they could "share positive feelings, appreciation, humor, and fun and find relief from difficulties." Mikayla observed:

> Everybody's just so brutal to each other in the outside world that it just makes you realize that you want to be kinder to each other, and you know, respect the other person., their opinions and stuff. So you know it is hard because….if you had to say something to another family member, you don't want to hurt their feelings. So, you do have to be careful of what you say.

She and her family found that active listening and allowing everyone to have their say in an open and honest way was most beneficial. This went along with the value Grace and her family placed on ensuring everyone was able to speak for themselves and striving to understand the perspective of the other person rather than imposing their own views on each other.

Sarah and her family set aside time at meals each day to make certain they connect with each other and keep communication open. This benefited them as they problem-solved through the challenges that came up for them. As a family, they were very open to sharing thoughts and feelings: “There are some times where (my husband) and I will share things just between the two of us, then sometimes we talk about how to broach it with the kids, but I would say for the most part we’re pretty open to sharing.”

Within Sally’s family, they have worked hard to understand each other’s communication styles as well as their nonverbal communication. They “spend a lot of time talking about what we need, and trying to be really honest with ourselves. And (she) has a different dynamic with each of my girls.” They communicate with each other how they want to be supported and make sure to include celebrations and gratitude in their daily communication.

Emily and her husband had very different communication styles:

> I’m very rush, rush, rush, and he’s like let’s pause and breathe so with that trying to honor each other’s communication styles…And sometimes, honestly, we have to remind each other that we’re a team because again, with our different thought processes, it can feel like we’re butting heads.

They were then more able to step back and find a common way to communicate and work toward their shared goal. In her journal, she pointed out that part of that communication was making sure to “truly listen to each other’s opinions/fears/thoughts, etc.”

In Helen’s work environment, she saw many instances where individuals were not open and honest about the disability a child had, leading the adults to work hard to not draw special attention to the fact that we are all different. She felt that in those situations, the child was the one who missed out:

> Their energy doesn't go into their school day. Their energy comes to pretending like whatever their "ism" (we call them, their ism), whatever it is, whatever there is missing, that's where all the energy goes and sometimes all the energy of the people around them. So we're just kind of blunt and honest all the time.

Within that, she allowed her girls to always have control over how they would like to communicate and what was important to them to get out of a situation.

In Ann's family, being able to share emotions with each other was highly valued. They found working hard "and helping the kids have the words to do that as they get older" was a priority. When they were successful, "they kind of have that positive reinforcement from each other and can build each other up." Reaching that level took everyone being very mindful of how they were communicating and working together as a family to hold each other accountable.

### *Self-Care*

Self-care is an area that looked different for every family and every individual. Helen spoke about self-care and the need to give yourself and those around you grace when facing difficult situations. When a professional she was working with felt bad about not having come up with a solution sooner, she commented: "We're learning together, it's okay. But it is like constant adaptation and you have to, like, forgive yourself for not having thought of it sooner or tried the thing that didn't work first, or you know, you just have to be okay with it." For her family, self-care meant really drawing into themselves as a family and becoming more of a self-contained unit. They worked hard to structure their time to ensure they were able to take the time to do little things for themselves like meditation, having a date night, or connecting with friends.

They felt the need to consciously carve out time “because when time gets away from you, that’s how things start to feel insurmountable. How you start to lose the connections that make you feel the most lifted.”

Ann felt the need to carve out time to make sure to connect with her husband as well: “We definitely try to make sure we have time for just the two of us.… If we are not strong together, we’re not going to be able to parent together.” As a family they make sure to “get outside of the house and make a concerted effort to go up to the mountains, or just kind of do things like that to change the scenery. For me, that helps my mental health.” Since she has a 15-month-old, her favorite self-care is to simply take the time to take a quick nap but she made sure her husband had the opportunity to spend time with his friends.

For Sally, self-care meant separating from her husband: “Because that gave me the empowerment and confidence and ability to be able to get her the resources that are most supportive to her, and speak my truth in a way that I didn’t have to take his position into consideration. It allowed me to be a better parent for her.” They were still sharing custody of their girls and they still had very different parenting styles; however, now Sally has the ability to create the environment within her home that she feels is most beneficial for her daughters. Within herself, she found support by seeking out community, those individuals with whom she could talk about things, and making sure she had time for things they all enjoyed.

Emily really needed to make connections with others for her own mental health: “Those phone calls or video chats with my sisters are very helpful for me.” At the same time,

> I definitely clung to my community just being in the EI world, and particularly since we don’t have family close by, having friends with kids that are comparable in the same age

> that also have a background in early childhood in early intervention… I relied on them a lot.

She emphasized that self-care needed to focus on smaller things since thinking of doing more grandiose things became too overwhelming and stressful, thus defeating the purpose. So, she focused on things like adding in time for a Starbucks run during errands, asking her husband to take the kids out so she could deep clean the house, and connecting with others. She and her husband made a point of holding each other accountable for taking time for themselves. Margie found more support from peers while her children were younger and now that they had grown, she was redefining what self-care meant for her.

Finding just a few minutes for themselves each day where they could be alone was important to many of the participants. Evelyn indicated, "I love being outside in nature, so anytime I can get outside to sit and read, that's always been my go-to time. And the shower is where I get most of my aha moments." Grace valued time alone outside as well: "Specifically in the summertime, my favorite thing is to drink my coffee out on the deck when it is nice and cool, or in the evening after dinner either me or my husband and I will just go to the deck and sit down on the couch." She varied what she did during that time but having the outside time away from her home office and free of demands was the important piece. Sarah found time before or after the kids went to bed as well: "It's usually getting up a little bit before they do and having some of my own time then… either I'm reading, or I have been in a routine of getting to exercise in the morning and then I always like to get my book out and read in the evening before I go to sleep." Ava and her husband work together to balance out their responsibilities with their kids to give each other the break they need.

Mikayla found support and renewal within her faith community and her strong belief in God. She felt like they "had a lot of other friends that had little kids, so I feel like we always had that, like I had a mom's group or whatever, and so I had that kind of support. And then obviously, our church friends and our church family. I think there was a lot of support there too." She found that while "it's very hard, especially when you have maybe a kid with special needs or something to feel like you can step away from that and not focus on it," it is incredibly important to do so. She and her husband were "trying to go out for a date night or something… and then trying to not talk about the kids… or a problem" that might be occurring. She found the little things to be most beneficial as well.

### ***Problem Solving***

When you have a child with low vision, problem solving becomes a required part of life. To allow them to access a world driven by sight, families in the study thought outside of the box and came up with creative solutions to include their child fully within family activities. On the survey, all families reported they often "collaborate in discussing and making decisions, and we handle disagreements fairly."

Helen had a very down-to-earth way of looking at problems:

> It's never like the fun thing, and sometimes like my kids would like to avoid it, but that's not gonna make tomorrow any easier…and so we kind of just play that angle like, will it make tomorrow better? And sometimes the answer is yes, because the answer is it doesn't matter that much.

Otherwise, they worked at problem solving through the situation. She made sure her kids always knew that even though they might struggle with having a certain conversation or with solving a problem "everyone has these conversations about whatever their crap is…. Everyone has to have those hard conversations, like that’s not a blind kid thing.” She felt it was important for her daughters to understand that problem solving is ongoing: “Just because it worked that one time in that one instance, it’s not the answer and (we are) teaching our kids the patience of it too.”

Emily and her husband approached problem solving by “drawing on each other’s strengths and trying to figure out the next steps.” This could be challenging at times as they

> have very different thought processes. Whereas if I see a problem, I’m like OK, here are four different solutions that I think are possible whereas (her husband) likes to hear all the information, take some time to process through all that information, and then come back to the table and have a discussion.

They needed “reminders that we’re on the same team, and we’re trying to figure out the same thing together, and we will figure out the same thing together, it is just they take different ways.” In their family, gaining information and having all the facts first became a very important piece of their problem solving. Information was important in Helen’s family as well and they would “sit down with a notebook and we will make a plan. That’s like one of our favorite things to do as a married couple. It’s like part of what made us who we are and how we like knew we should just be together forever.”

Sally, Ava, and Mikayla found it was important to first identify what was truly the underlying problem, not just what was seen on the surface. Sally worked with her girls to answer a set of questions about each problem: “What did you learn about that?....Will you survive this and what might that look like?....How do you feel?... What story did you make of it?.... Which of those four stories might be true?” All of the families really spoke of honoring the uniqueness of each family member throughout the problem-solving process. Helen spoke for them all when she said:

> We don't like pretend it's not there…. Sometimes we talk about that being the problem, and is it a big deal? Little deal? Do we want to face the problem? Because like if you pick every battle for all time, that's exhausting in itself. And then what part of the problem do we want to address? …. Is that person affecting your education? And how worth it is it? Because…any human could sit there and find all the problems.

This idea of picking your battles was echoed by other families as well. Grace and her family looked at all the angles of a situation and decided "is it worth the squeeze so to speak" before they spent the energy to problem-solv through it. When they determined it was worth it or necessary, they spent time looking at each piece of the activity and worked together to find ways to make it work by drawing on the different views they each brought to the problem. Margie and her family "do a lot of brainstorming and just talking through how do we make this easier, are there resources out there, or is this just something we are not going to tackle." Margie saw that finding the balance took the effort to "always support each other and work as a team through everything" and creating a "collaborative process…versus me trying to navigate everything." Margie was joined by other families in relying on "lots of research" into the various facets of the problem and possible solutions before picking the one that was best for their family.

Sarah journaled that her family approached challenges by "talking about potential solutions together as a family, talking to others who have faced the challenge before to see how they met the challenge, and researching by questioning TVIs, orientation and mobility specialists, and ophthalmologists." They worked closely together as a family to find a solution that met everyone's needs. While most families preferred to look at all the different facets of a challenge, Ava's family often did not "really think too far into things. We just kind of play it step by step… you could either go this way or that way." They found it became easier to remain positive when they were not overwhelmed by too big of a situation at once.

Evelyn and her family were in a unique situation to provide modeling for their son. Because they both have visual impairments as well, they provided daily examples of how they looked at a situation and worked through the different ways they would be able to move past that situation by minimizing the impact their decreased vision had. Evelyn often told her son, "Ok this is how I do it, but if this doesn't work for you, now that you've got an idea, you may come up with a faster, better way to do it for sure."

Ann's family made sure they were constantly "looking at the end goal first. We ask what do we want to accomplish here?" They made sure to use this process whether they were problem solving as a couple or involving all the kids in the process as well. If the kids were involved, they took "into account everyone's perspective by asking age-appropriate questions for each child." Emily and Ann both found it to be necessary to acknowledge the role anxiety played in the process. Ann journaled "we also have to take into account our anxiety and how that can take away from our process so we allow ourselves the space to 'freak' out about something and then can recenter ourselves to focus on the issue at hand."

All families who had children who were old enough worked at modeling for and providing the necessary skills to their children so they could develop their own problem-solving skills. Helen even had it written into her daughter's IEP that "she has to try and solve the problem first, and if she can't solve the problem herself, then the teacher helps to solve the problem…but she tries her resources first." Mikayla's daughter has developed her problem-solving skills to the point that when she is told she cannot do something because of her visual impairment, "She is the one who will try the hardest to prove you all wrong. Like she ran crosscountry (independently)…even though it was hard and there was a lot of obstacles, she would do whatever it takes to figure out how that would work." Part of her success as a problem solver was "she was taught at a very early age to advocate for herself, so …. that was helpful." Evelyn worked hard to make sure that when her son had learned a certain skill at school or during mobility, he was "given opportunities to use (his) newfound skill, whether it be preparing something in the kitchen, or expanding on that skill by offering them opportunities like planning out a trip if we're going out." This allowed him to solidify his problem solving using that skill in a new situation. Strengthening each family member's problem-solving skills helped participants become stronger as a family.

## Research Question 3

Risk factors and protective factors came together to create higher or lower levels of resiliency within families. Research question three asked what are the challenges families of children with visual impairments experience and how have they overcome them? To answer this question, both the risk factors and the protective factors present for participants were synthesized together.

Unsupportive professionals appeared in different ways for each family; however, they all moved forward in somewhat similar ways developing a reliance on educating themselves and strengthening advocacy skills. For Helen's family,

> We kind of just decided that medical information is great, but everyone tells us over and over and over again 'well, there's nothing I can do about it' and so if that is how they choose to feel about it, we are the ones who will have to do something about it. So, it changed our whole mindset from being in an aspect of like we need to seek out help, we

> need to find the people who are going to help us be what’s best for our kids, to we are those people and other people can come ask us what they can do to help with our kids.

Taking control of the situation and switching their mind from dependence to control allowed them to move forward positively. Fierce advocacy based on extensive knowledge became the strategy they used. Education became a force that allowed them to exert control over a seemingly uncontrollable situation.

Sally found comfort in education and becoming an expert as well. She had multiple negative experiences with professionals leading her to be “a researcher.” So, when her daughter struggled with traveling in new environments, she drew on her research skills:

> The part we’ve rubbed up against in the past is people at her school saying, oh she navigates her environment fine (so no need for orientation and mobility). I’ve had to like observe her and try to figure out where the sticky points are, and then try to figure out how to support her with that.

Becoming her own expert allowed her to help her daughter gain comfort in traveling. Sarah dove into research to be able to strongly present her side of the argument at IEP meetings to ensure what was best for her son became a part of his IEP. Gaining knowledge and the confidence to advocate for themselves and their children allowed these families to move forward past the negativity created by unsupportive professionals.

Grace increased her reliance on trusted professionals within her world to fill in the gaps. When presented with an unsupportive professional, “we just had to not talk about that with them, and we just talk about it with the actual experts in the field, or (my daughter’s) teachers, paras or vision team.” Evelyn dealt with unsupportive professionals by finding others who were willing to work as a part of the team or to support things like braille, which she felt were important for her son.

All families started from a belief that they had control over their environment as well as the effects of the visual impairment on their family, giving themselves the confidence they needed to advocate for their children. When faced with a lack of trust that her daughter's needs would be met, Sally fell back on taking control of what she could and pulling in other professionals along the way: "The way that I have found that works the best is for me to have a good relationship with her case manager at the school level and her vision specialist so I can delegate to them, and put that on their plate for them to have that conversation."

Finding a new group of professionals or even just a single positive professional allowed families to begin to redevelop trust and move forward positively. Emily stated, "It's ensuring that the people in her life and her circle are still there to support her and that she can advocate for herself….so definitely early intervention and having that support have been huge." Mikayla found the same relief when she was able to move away from "the doctor that didn't diagnose her correctly" to a pediatric ophthalmologist who completed the necessary tests to diagnose her daughter correctly. All participants found support from TVIs and orientation and mobility specialists even if they were just encountered for short times at special events. Having just one or two trusted professionals counteracted the negative effect of unsupportive professionals and allowed study families to move forward with confidence.

Families combined their locus of control, acquired knowledge, advocacy skills, and strong familial relationships to develop strong problem-solving skills to help them counteract negative outside influences. When Helen's

> daughter had a teacher last semester that was like not very interested in honoring her needs at all. And we started with like having her talk to him and like she made a whole intro video because RP is so weird, like you try and explain it to someone and they’re like I’m sorry but what? So, she made like a little explainer video.

They moved from there through further steps that eventually led to a change in teachers. Without the confidence provided by their knowledge base and their support of each other as a family, they would have been unsuccessful in making that change. When faced with inaccessible environments, Margie and her family immediately begin to problem-solv “which type of equipment do we need? And do we need a car or do we need to rent a car? How many people do we need? Can I do it independently?” This allowed them to control the situation as much as possible before they entered it and to “make sure that everyone’s individual needs are met.” Without problem solving they would have been unable to travel and would have been dependent on their familiar home environment.

Negative societal perceptions came into play for every family; however, none of them allowed those perceptions to change their belief in their child or negatively influence how they functioned as a family. Ann and her family “just kind of move past all the looks. You get used to it, and kind of tune it out.” Grace felt the same; when faced with negative reactions in public, she simply chose “to ignore it.” Sally stated:

> Low vision seems not to be the understood entity in the wheelhouse of a lot of people in public…. I’ve become more of an upfront advocate. So, instead of waiting until something happens, I will approach her teachers and say she seems to function as a sighted child here, or something she might be struggling with that might not be on your radar is. If these types of things happen here’s how you can….

Sally and Evelyn embraced the idea that there would be uncertainty in the community and chose to combat it with upfront education. When Evelyn saw others staring or heard comments, "I'll just walk over and say 'Hi! This is (my son) would you like to say hi?'" She then proceeded to talk to them about visual impairment. Margie's family went the route of educating others as well: "It's still hard when kids will stare or will ask, why are you in a wheelchair, why can't you walk, or so trying to empower her with the words to be able to explain the situation…Have her have the ownership of that." By building the capacity within her daughter, she was not only educating the public but allowing her daughter to develop an important self-advocacy skill. Falling back on their strong acceptance of their children's visual impairments and the recognition that other's perceptions did nothing to diminish their actual ability helped them to move forward. The strong relationships built within their nuclear families, extended families, and chosen community supports provided a buffer between themselves and negative societal perceptions as well. Margie journaled that "our individual personalities, ...along with help and support from family and friends all contributed to how we overcame each challenge we faced."

The large variety of low vision diagnoses as well as the vastly different approaches families took in dealing with the diagnosis made finding support within the visually impaired community difficult for participants. Each family in this study took a very proactive approach to their child's visual impairment. They all believed strongly in maximizing independence for their child, collaborating closely with the professionals in their world, and advocating strongly when they felt their child's needs were not met. Many other families did not choose this route. Therefore, participants encountered friction when looking for support from other parents of children with visual impairments. Helen noted, "I really do feel like we have chosen to handle this a lot differently than a lot of other people, … so when I talk to other people like sometimes we leave those situations feeling bad about ourselves." Instead, they found support with others who had had difficult things happen with their own kids. "It was still like easier to sit and talk to someone who knew about like hard things happening to your kids." They also chose to be mindful of what social media support to take and found more support in groups with families of kids with other diagnoses rather than visual impairment. Emily journaled:

> Though we do not know a lot of other families with children with VI, we have met families whose children also have diagnosis. Although it is not the same, it is nice to be able to discuss (and at times commiserate) about numerous appointments, shared therapists, looking at school options, etc. with other parents that understand.

These families all had a need to find supportive communities outside of their homes; they just found those communities in diverse places.

Uncertainty can be very unsettling for anyone. The participants in this study were no exception. Margie found that looking for the positives or accomplishments of her daughter was beneficial: "Other times where she's overcome something, is part of something amazing, and you're just super proud because this is your kid." Celebrating accomplishments became an important piece for families. In Ann's family, they "usually sit down at the dinner table and talk about it so that everyone hears whatever it is. So, you know they've had their positive moment that we celebrate." Her daughter's father did things a little differently and "they almost have a party, his parents come down and it's a huge celebration." Sarah's family acknowledged accomplishment by allowing the person being honored to choose the activity they did as a family or the meal they ate. Ava journaled that their celebration involved "lots of treats! We all have a sweet tooth." Grace's family would change up their celebration based on the accomplishment, but all participants found it to be important to celebrate family members’ accomplishments in some way.

Families looked to different self-care activities to combat the stress. Helen noted that when her family did not make the time for those self-care activities, “that’s how things start to feel insurmountable. Right? How you start to lose the connections that make you feel the most lifted…. So we have learned quickly that we have to like help protect that for each other.” Ann felt strongly that taking care of yourself first allowed you to have the emotional capital available to support others and deal with difficult things.

Building a strong knowledge base allowed families to have the confidence they could face any difficulty and know what to do providing reassurance. This knowledge came from professionals as well as their own research. Sally commented that when she received her daughter’s diagnosis:

> There was just a lot of not knowing, and that can be an unsettling place. But even at the time you know, I had surrounded, I had looked into the resources that she could need, and we were going to the anchor center, and we were having OT come to our house, and so I for the most part have a lot of radical acceptance about a lot of things.

All other families felt the information they were able to gather provided them with the certainty that even if the diagnosis ended up playing out as the worst-case scenario, they would still be prepared. Ann felt that information gathering “supplements everything else we’re doing. We try to you know find control in that capacity as well. It’s just being really knowledgeable about whatever issue we’re going through.” This allowed them to approach each new challenge as just a small bump in the road to be moved around rather than a large hurdle that could not be surpassed.

## Conclusion

Walsh’s family resiliency theory provided a framework to study more closely the various protective factors present for families when presented with what could be overwhelming risk factors. Within this study, common themes in both risk factors and protective factors emerged for the families studied. In the area of risk factors, they were faced with the need to build trust in others after interactions with unsupportive professionals. They faced the uncertainty of what their child’s diagnosis would mean and were challenged by not fitting into either the sighted or the visually impaired world while dealing at times with negative reactions from those around them.

In the area of protective factors, supports they found came from their personal attitudes about visual impairment, their positive attitudes when faced with challenges, and how effectively they felt they were able to control their worlds. For every unsupportive professional they faced, they were provided with an equal or greater number of supportive professionals and family members. Their challenges allowed them to build stronger relationships, communication styles, and problem-solving skills within their families. They recognized that setting attainable goals for their families, becoming fierce advocates for their child’s needs, and making time for self-care were imperative pieces of their success.

While each family came into their difficult situation with their own set of background experiences and beliefs, they were able to pull from those experiences in similar ways to create a strong pattern of resiliency as a family. Margie in her journal provided the strongest argument for developing strong family resilience when she shared that her daughter felt “her resiliency comes from (her family) and the ways they were able to show her there was a place for her in the world. Despite there being times when she was younger that she wanted to run away from or not deal with her challenges." The families in this study provided evidence that a strong foundation in family resilience had allowed their children to move forward into the world in a positive way.

# CHAPTER V

# DISCUSSION AND CONCLUSION

The definition of resiliency has changed over time with early researchers focusing on individual characteristics or innate qualities that allowed people to move forward positively (Fletcher & Sarkar, 2013; Masten & Monn, 2015; Walsh, 1996). Families were viewed largely as contributors to the stress or adversity in a situation rather than potential sources of strength or protective factors (Walsh, 2016a). Slowly, views began to switch to more of a combination of nature and nurture (Fleming & Ledogar, 2008) and with that switch, researchers began to see families as a possible source of strength as well as adversity (Greeff & Van Der Walt, 2010; Werner & Smith, 2001). Throughout every stage of research, and within each individual study, the definitions of resiliency morphed and changed; however, they always kept two main components: (a) adversity and (b) positive adaptation to the adversity faced (Armstrong et al., 2005; Fletcher & Sarkar, 2013). Within this study, resilience was defined as a dynamic process in which families utilized their strengths and resources to withstand and rebound from a crisis or adversity to move forward stronger. Resiliency is a fluid process. A family’s capacity for resilience changes from situation to situation as the members within the family grow and change (Fletcher & Sarkar, 2013). Resiliency could be measured not only by a family’s response to stress over time but their response to the stressors present in the current moment for them (Fletcher & Sarkar, 2013). Results from this study provided a snapshot of families’ resilience at the current moment rather than a guarantee they had been or would be resilient in every situation.

## Restatement of Research Problem

The purpose of this study was to look at the experiences of families of children with low vision to gain a better understanding of their exposure to risk factors as well as the protective factors they found most beneficial. Much research has been completed on the factors that contribute to resiliency in families including families of children with disabilities (Bekhet et al., 2012; Halstead et al., 2018; McConnell & Savage, 2015; McConnell et al., 2014; Muir & Strnadova, 2014). However, little research existed specific to what factors influenced families of children with low vision in either a positive or a negative way. The risk factors present were well documented (Bambara et al., 2009; Lupon et al., 2018; Ulster & Antle, 2005; Zegeye, 2019); however, little emphasis was placed on which protective factors benefited this group of families the most. This study sought to determine which risk factors were most impactful for families of children with low vision and how they applied protective factors to help mitigate that impact by investigating the following research questions:

Q1 What role do risk factors play in the experience of families of children with low vision?

Q2 What protective factors do families of children with low vision perceive to be most beneficial?

Q3 What are the challenges that families of children with visual impairments experience and how have they overcome them?

The study was completed as a phenomenological study to explore the lived experiences of families of children with low vision without placing any predetermined judgment on their stories. Following the analysis of a resiliency survey, two interviews, and journal prompts, multiple themes for both risk factors and protective factors emerged. The area of risk factors included (a) unsupportive professionals, (b) trust, (c) finding a place, (d) society's reactions, and (e) uncertainty. Protective factors that played into family's successful resilience were divided into three main categories (belief systems, organizational processes, and communication processes) based on Walsh’s family resiliency theory. In the area of belief systems, the important themes were (a) positive outlook, (b) acceptance of visual impairment, (c) locus of control, and (d) religion. In the category of organizational processes, significant themes were (a) advocacy and information gathering, (b) outside support, (c) supportive professionals, and (d) technology. In looking at communication processes, the themes that stood out were (a) goal setting, (b) changing relationships, (c) communication, (d) self-care, and (e) problem solving.

## Findings Related to Current Research Literature

### Research Question 1

The data gathered for research question 1 (What role do risk factors play in the experience of families of children with low vision?) showed that for participants in this study, risk factors served as a catalyst to increase their overall strength and commitment as a family. Extra hardship led these families to lean more heavily into the protective factors present in their world (Walsh, 1996). When presented with adversity, participants turned it into a catalyst for change. Lack of trust in the professionals around them drove them to search harder for information to become the expert their child needed. Unsupportive professionals allowed them to forge stronger bonds within the family and to seek out other more positive connections within the community. Lack of a clear place to land and negative societal perceptions led them to examine within themselves what they thought and believed about their children’s visual impairments. It pushed them to seek out others who were familiar with dealing with difficult things to build a strong support system. The uncertainty they faced daily brought them more motivation to educate themselves on their child’s visual impairment as well as pushing them to make sure they put into place ways to care for themselves throughout the process. Every family felt the visual impairment had made their family more empathetic and aware of those around them and the struggles they went through as well. So, for this group of participants, the risk factors present served to strengthen them and provided them with the opportunity to see the world in a slightly different way.

### ***Disability***

Past and current research focused on the presence of the child's disability and the accompanying implications as one of the largest stressors for families. Often dealing with a child's disability required families to change their family dynamic, gain new knowledge and skill sets, and allocate resources in different ways (Bekhet et al., 2012; Halstead et al., 2018; McConnell & Savage, 2015; McConnell et al., 2014; Muir & Strnadova, 2014). In past studies, this change often led to disfunction within the family if they were unable to find the correct balance between stressors and protective factors (Bambara et al., 2009; Greeff & Van Der Walt, 2010; Heiman, 2002; Ulster & Antle, 2005). While the families in this study all had to substantially change the way their families functioned, those changes did not produce the largest risk factors for them. In fact, many of those changes ended up being the factors that allowed them to be most successful. Multiple families felt that prior to receiving a diagnosis of visual impairment for their child, they had been so caught up in the day-to-day routine of their lives they felt as if they were more business partners than life partners. Having the diagnosis of low vision forced them to make changes in their schedules and communication patterns that drew them closer together so they could provide support for each other. Having unsupportive professionals pushed them toward expanding their knowledge base so they could form a united front while advocating for their child. Problem solving together made them more conscious of each other’s communication styles, strengths, and challenges, allowing them to develop stronger communication skills.

Families often struggle with the unknown when faced with a new diagnosis for their child (Leyser et al., 1996; Lupon et al., 2018; Ulster & Antle, 2005). They found it difficult to know what independent living would look like long-term for their child and how to build goals and dreams around that (Leyser et al., 1996; Lupon et al., 2018; Ulster & Antle, 2005). In past research, it was noted that families of children with low vision tended to deal with more stress than families of children who were completely blind (Lupon et al., 2018; Ulster & Antle, 2005). The scope of this study did not allow for the comparison between families with children who were LV and those who were completely blind. However, this one disability-specific area did seem to have presented issues for the families in this study as uncertainty was inherent in a diagnosis of low vision. Often those diagnoses came with the potential for progressive loss or there was initial ambiguity around how a condition would affect their child as there could be large variance within each diagnosis. Humans naturally want to find order in their world and want to have the ability to know what is coming next. This creates discord as families tried to come to terms with how to plan for the future amidst the unknown. Study families initially felt sadness around the worst-case scenario options they were given and were unsettled by the vagueness of what the future might hold. One mother spoke of creating worst-case scenario dreams for her child around driving and having to walk herself back and remind herself that they might never happen and even if her daughter was sighted, she could have made similar choices around driving. Families within this study relied heavily on gathering as much information about their child’s visual impairment as possible and becoming fierce advocates for them to counteract the increased uncertainty.

### ***Community Resources and Connections***

Families in this study struggled most with inadequate community resources and connections. Similar to other research in the area, participants in this study found it challenging to find quality providers who were able to match their style to that family's needs or providers who were even knowledgeable enough about their child's visual impairment and its implications to help them move forward (Jessup et al., 2019; Lupon et al., 2018; McConnell & Savage, 2015; Muir & Strnadova, 2014). Both parents and their children struggled to fit into the sighted world. It became hard to build a community around the low vision diagnosis due to the vast differences in the implications of such a diagnosis and yet, the child and family did not fit into the sighted world either. Social interactions became the most impacted for children while their parents failed to have the ability to take full advantage of a support system built from common experience.

Families faced harsh judgment for the choices they made in how to parent their children as well as how they chose to access services to the point where one family was turned in to child protective services for choosing to go a different route with their care. In multiple cases, the professionals misdiagnosed their children or attempted to submit them to procedures better suited to adults. All the families with school-aged children had experiences with professionals within the school setting who had refused to include their child or to follow through on the accommodations listed on their IEPs.

Finding their place in society proved difficult for them as their child did not really fit into either the sighted world or the world of other students with visual impairments. This created difficulties for families seeking commonality with others. In past research, support of others with similar disabilities provided families with substantial support for not only their children but the families as well (Muir & Strnadova, 2014). Support groups played a role in providing significant support and reassurance for families (Peer & Hillman, 2014). One surprising result of this study was while families felt that having peers who were visually impaired was a positive for their children, they felt they themselves received better support from other families who had dealt with difficult things rather than those with visual impairments. Families within this study held the belief their child would be capable of doing anything they chose with a few adaptations and expected the same from them as they would any sighted child. They had fully accepted their child's visual impairment and pushed them to meet their full potential. Because of this, they often felt judgment around how they chose to parent their children from other parents of children with low vision and more empathy from other people whose children had struggled even if the struggle was very different.

### ***Societal Perceptions***

As was found in past research, families did not exist separate from the society around them and in that way they were subject to the pressures and beliefs of that society (Bitsika et al., 2013; Heiman, 2002; Lupon et al., 2018; McConnell & Savage, 2015). Members of society as a whole have such varied perceptions of visual impairment, fear of what it would mean to lose their own vision, and misguided ideas of how to "help" those with visual impairments. Families and children with visual impairment constantly work against the negative perceptions of others just to complete simple activities in the community. The families in this study felt those pressures from within their own extended families as well as when they took their children into public with their canes. They felt the weight of the pity they received from family members and their occasionally misguided attempts to "help." They were upon occasion shamed for how they chose to parent their children and for the ways they pushed them toward independence. The way they were singled out and responded to in public on occasion made them or their children hesitant to continue to use needed supports such as long white canes or to share with others about their visual impairment.

Often children and families when faced with the pressure of a visual impairment fall into a pattern of learned helplessness, become overly protective, or overly impressed with their child's accomplishments and fail to move them forward to meet their potential (Bambara et al., 2009; Lupon et al., 2018). The strong profiles of protective factors developed by the participants prevented them from giving in to the pressure they felt and kept them on the path of high expectations. Otherwise, there was the potential for much more negative outcomes for their child and the family as a whole.

### ***Parental Mental Health***

Parental stress and mental health challenges such as anxiety and depression were found to be impactful on overall family resilience (Bitsika et al., 2013; Cramm & Nieboer, 2011; Halstead et al., 2018; McConnell & Savage, 2015; McConnell et al., 2014; Peer & Hillman, 2014). Grief could influence a family's ability to move forward as well (Bambara et al., 2009; Heiman, 2002; Tuttle & Tuttle, 2004; Ulster & Antle, 2005). However, in this study, families did not report any long-term negative impacts on their mental health. They all had a healthy recognition of how difficult it could be to have a child with a visual impairment and how they had gone through periods of feeling bad that their child would be unable to see the same as others; however, they were short-lived and did not permanently impact their resilience. They did not identify as being anywhere in the grief cycle. When they mentioned grief at all, it was in relation to others in their extended family rather than themselves. This could have been a result of screening participants and choosing them based on a high level of self-reported resilience.

The one area where they were more challenged was trusting in others around them to care adequately for their child. They worried their child's safety would not be adequately monitored and they themselves unconsciously provided supports to their child to increase their success that would not translate well into other environments. Each parent held their child to high expectations and they worried those same expectations would not carry over into the school or community environments. The occasional unsupportive professional they encountered exacerbated their lack of trust. This often led them to be continually on guard and to open up to and depend on only a few select professionals in their world. Instead, they felt compelled to become their own experts and closely monitored the professionals working with their child.

## Research Question 2

In answer to the research question of what protective factors families of children with low vision perceived to be most beneficial, we need to look at a combination of many different factors. Participants within this study relied heavily on connections they made within their nuclear families, extended families, and with a small group of trusted community members. They developed strong positive perceptions of their child's visual impairment, believed they could control their world and the visual impairment, and looked at the world through a positive lens. Problem solving, open and honest communication, and making time for self-care allowed them to develop stronger relationships within their families. They utilized technology to gain information and remain connected with others and sought out resources to allow them to become experts on their child's visual impairment. They set goals within their family that enhanced their connectedness and looked to link their children with others who had similar disabilities. The robust portfolios of protective factors demonstrated by the families within this study allowed them to move forward positively and matched well with what was found in past studies.

### ***Belief Systems***

In Walsh's family resiliency theory, the belief system looked at meaning-making, positive outlooks, and spirituality (Walsh, 2016a). Families' attitudes toward the stressors in their lives, their locus of control, as well as their religious beliefs were the most impactful for families within the larger pool of research (De Klerk & Greeff, 2011). This correlated well with what the families in this study reported. They were all able to take their child's visual impairment and accept it as just another piece of who their child was, something that made them unique rather than a negative component. They believed that though their children might face more challenges, they would overcome them and they held their children to high standards. They were not blind to the challenges in situations but felt the positives were more prominent and the negatives were there to be learned from and moved past.

Participants emphatically felt they were in charge of their situation and even when they needed to spend more time and energy on the visual impairment, they were still in firm control. They acknowledged there were factors from outside their family that influenced the direction they went as a family but, ultimately, they made the final decision on their own. When they did face points where the visual impairment impeded their path forward, they would stop, plan through the situation, and change things moving forward so it would no longer be an issue. This echoed the current literature that indicated having an internal locus of control increased coping and decreased stress (Bekhet et al., 2012; Greeff & Nolting, 2013; McConnell et al., 2014).

In past research, belief in God allowed families to trust that God would not give them more than they could handle and allowed them to make meaning of their struggles (De Klerk & Greeff, 2011; Greeff & Nolting, 2013; Greeff et al., 2012). Religion played a larger role in past studies than it did in this one. Within this study, only 5 of the 10 participants cited religion as a mitigating factor for them. The participants for whom religion was a driving force relied heavily on it. It became one of their strongest supports. They spoke of it allowing them to make meaning out of why things were happening and gave them a sense of hope that they could overcome difficult situations. This paired well with past literature that found religion allowed families to passively accept their situation, decreased parental depression, and built community connections (Bekhet et al., 2012; Greeff & Nolting, 2013; Quintero et al., 2021).

### ***Organizational Processes***

The organizational processes section of Walsh's theory encompassed flexibility, connectedness, and social/community resources (Walsh, 2016a). Past research centered around the systems families developed within themselves, their flexibility, and how they utilized the supports they found in the community. It was found that families where there was a higher overall education level sought out more resources than did less well-educated families (Greeff et al., 2012; Zegeye, 2019). This was true for the study participants. The average educational level of the participants in this study was high with seven participants having a master's degree. All families reported that seeking out the resources to educate themselves on their child's visual impairment, available services, and appropriate interventions was one of the most important things they had done. This allowed them to become fierce advocates for their child no matter what situation they found themselves in.

Past studies found connections with others outside of their immediate family (extended family, professionals, friends, etc.) proved to increase the likelihood that families would develop strong resilience (Armstrong et al., 2005; De Klerk & Greeff, 2011; McConnell et al., 2014; Peer & Hillman, 2014). Like families in these past studies, those in this study sought supports from outside of their families. This looked like seeking out peers who were visually impaired for their children. For themselves, they preferred to find support from other adults who had had difficult things come up with their own children. Those supports were found in professionals, family members, and friends. Though some professionals had created a risk factor for study families, they were all able to point to an equal number of professionals who were invaluable resources for them. This was especially true of the TVIs and orientation and mobility specialists in their lives. Technology became an inanimate support for them as it allowed them to make connections with important people and information in a way that would have been impossible otherwise.

It is important to note the difference between the amount of support received by families in relationship to how they perceived that support. Received support was the amount of financial, social, and informational help that was provided to a family. Perceived support was how well the family accepted the support that was provided and how beneficial they found it to be. The best outcomes occurred when families perceived the support as beneficial even if the quantity of the support was small (Bambara et al., 2009; Bayrakli & Kaner, 2012; McConnell & Savage, 2015). Within this study, participants were all able to point to higher levels of perceived support and had no problems putting aside received support they did not find beneficial.

### ***Communication Processes***

Walsh included clear information, emotional sharing, and problem solving/prevention in her communication processes (Walsh, 2016a). Past research highlighted the importance of developing strong and affirmative communication within families (Bekhet et al., 2012; Greeff & Nolting, 2013; Greeff & Van Der Walt, 2010; Muir & Strnadova, 2014). It emphasized that problem-focused coping styles increased the likelihood a family would develop resilience long-term (Mackay, 2003; McConnell et al., 2014; Peer & Hillman, 2014).

Peer and Hillman (2014) pointed out that problem-focused coping strategies using analysis and planning to help families move forward proved more effective over time. Problem solving was a driving force within the families who participated. They felt strongly enough about it that they not only regularly depended on it, they also put considerable effort into teaching their children how to do it effectively. For the majority of them, it was a collaborative process within the family, utilizing every member's strength and making sure to honor everyone's process and wishes.

Normalizing the idea that problems are a part of everyone's life assisted study families and children with accepting that even though their challenges might center around visual access, others were dealing with their own issues so they were not the only ones struggling. When families worked together on solving problems, it provided important opportunities for kids to learn within real world contexts. Families felt that individuals with low vision have to problem-solv their entire lives so the sooner they begin to build a repertoire of problem-solving skills, the better it would be for them long term. Problem solving as a family helped prevent one family member from becoming overwhelmed by having to deal with all the issues present and drew them closer together as a family.

Strong communication is required in order to develop shared decision making and requires negotiation and compromise (Mackay, 2003). Open and honest communication strategies allowed families to affirm each other and develop positive relationships (Greeff & Nolting, 2013). Communication and relationship building helped these families to take the need to redefine family roles and made it into a positive force within their families. They all had changed the way they interacted with each other to ensure they could be more present for each other to provide the support needed to move forward positively. They talked about refocusing on relationships rather than work and made sure to respect each other’s differences. This required them to have the open and honest communication found in other studies within their own families.

Focusing on common goals leads to successful outcomes (Greeff & Nolting, 2013; Peer & Hillman, 2014). Goal setting around increasing family connectedness and making sure to take time for self-care were common themes for study participants. Although the goals they set and the ways they chose to care for themselves were different, the results allowed them to move forward as more cohesive family units. Many families spoke about not only making sure to take time together as a family and setting family goals but supporting each individual family member’s goals and need for self-care activities as well. Ensuring they celebrated individual family member’s successes as a family played a large role in this area.

## Research Question 3

The above themes served to answer research questions one and two. Research question three regarding the challenges that families of children with visual impairments experienced and how they overcame them required the synthesis of both the risk and protective factors together to determine the interplay between them.

Just as in past studies, unsupportive professionals provided every family with a differing level of challenge (Lupon et al., 2018). However, they each approached those challenges in somewhat similar ways. They used the challenge to push themselves forward into becoming even more knowledgeable about their child’s visual impairment and the processes that went with it. In some cases, this created fierce advocacy within the family and in others, it simply reinforced it. They relied on their internal locus of control and the belief they could influence what happened in their world and set out to make it different. Often this meant looking for other supports outside their family to balance out or replace the negative influences. They relied heavily on their shared problem-solving skills and the strong relationships they had built. When lack of support created issues with trust, they were pushed to seek out professionals in their lives whom they did feel confident in and relied on them to provide the necessary training and support when they could not be there.

The adverse reactions they faced from society mirrored that of past studies (McConnell & Savage, 2015). Negative societal perceptions made them more reliant on each other and the positive professionals in their world. They all faced the negativity, took a step back, regrouped, and moved forward stronger in the knowledge that some people were never going to fully understand. They might stare or make negative comments but that did not diminish who their child was or change their belief in them. Their strong acceptance of their child's visual impairment and how it had shaped them made them confident in facing other's doubts.

As families struggled with finding their place within either the visually impaired community or the sighted world, they relied more heavily on those connections they made with other individuals who had had hard things happen in their world. They sought out more resources to support their child in a different way or found places where they and their child were able to have positive interactions. They set goals as a family that would allow them to become even stronger supports for each other and changed the relationships within their families to meet the needs not met elsewhere.

Uncertainty created a very unsettling environment for families (Leyser et al., 1996; Lupon et al., 2018; Ulster & Antle, 2005). Participants faced the uncertainty of their child's visual impairment by increasing their knowledge about the possibilities and what they could mean for their child. They sought out new resources such as braille education that could help their child if they did one day lose more vision. They made sure to incorporate self-care so they were in a better place themselves. They came to accept that no matter where the visual impairment took them, they would be prepared and still in control of it rather than letting it control them. Putting experiences into their child's life that would allow them to experience as much as possible before any potential vision loss became more important for many families.

Overarching all the challenges they faced was their ability to find and focus on the positives in each situation no matter how stressful it might be. They leaned on the positive people they found in their lives and relied on technology to assist them in getting necessary information and to make the connections they needed with others. Their focus on positive communication and honoring each person's perspective and approach allowed them to build strong family ties.

## Implications for Practice

As professionals, we are unable to influence in a substantial way most of the risk factors or stressors that enter the lives of the families we encounter. Instead, focusing on helping to strengthen the protective factors present provides us the best avenue to affect change. The common protective factors found in this study helped give us direction for how we could change our practice. Based on the results from this study, the implications for practice include (a) providing families with positive professional interactions, (b) making families true partners in the process for their child, (c) supporting families in information gathering at a level that meets their needs, and (d) connecting families to resources.

## Positive Professional Interactions

We can fulfill the needs families have for positive rather than negative professional connections. Active listening becomes important for families to feel as if we are focused on what they are sharing and understanding their perspective. Seeing each family as unique allows us to match our responses to their needs. Having a positive attitude that accepts the family's feelings, both positive and negative, and approaching challenges with a calm attitude assists families in moving forward.

## Family Partners

Professionals who listen to the family's perspective and take it into account in decision making empower families to take more control of their child's educational process. By seeking out their goals for their child, we are able to incorporate those into our own goals and we make them a partner in the process. When our goals do not match with their goals, open and honest conversations will allow us to understand our differences and move closer together. Recognizing that parents' goals have an equal value to ours allows us to welcome them into the educational process. Listening to their concerns and problem solving around them helps to make them feel welcome in the school and allows them to see us as valuable partners with them for their child.

It is important that we take into account the differences within each family that come with their culture, past experiences, belief systems, and goals for their family. Doing so will enable us to better understand where they are coming from in order to become problem solving partners with them and allow us to better understand where they are in the process of accepting their child's visual impairment. Having that understanding could help us to more easily empower our families and hopefully help them to begin to develop the internal locus of control necessary to allow them to feel more in charge of their worlds.

### Information Gathering

Every family is at a different place in the process of accepting and moving forward from their child's diagnosis of visual impairment. As professionals, it is important that we take the time to listen to families and determine where they land in that process. At each point, they will be ready for different amounts and types of information whether it be just the basics on what the diagnosis means and how to navigate the medical system or how to push their children to reach their full potential. It is important for us as professionals to be ready to either provide them with the information they seek or to problem-solv with them where it can be found. Making an appropriate match between their current level of need and the information provided prevents us from overwhelming them and potentially leading them to shut down. It allows parents to trust in our regard for them and their children and furthers strong partnerships.

### Resources

Part of this information gathering includes connecting parents to appropriate resources outside of our control. This might take different forms for each child. Some might need connections to where to find appropriate medical care or resources for equipment for their child to use at home. Others might desire connections for activities for their child to participate with other children with visual impairments or ways to make existing community resources accessible to their child. Connecting families with other families could be beneficial in some instances to allow connection between children. Adults would have the opportunity to form connections as well if desired.

## Limitations and Implications for Future Research

While this study had families whose children were at various points in their educational process as well as having had their diagnosis for varying lengths of time, other areas would have helped to increase the transferability of the results. Although the focus was on resiliency within families, the main participants were all mothers. They spoke about overall family processes and practices; however, having viewpoints from fathers, the child with low vision, and any siblings as well would have created a more well-balanced perspective. The families included in this study were taken from a sample of convenience as they were all nominated by TVIs within the metro area in one state. Requesting that TVIs nominate certain families presents an inherent bias as the original TVI must make a judgment around the level of resiliency shown by families before bringing them to the attention of the researcher. This could lead to the exclusion of some families from different cultural backgrounds. Drawing from a bigger, more national sample or one where all families were allowed to fill out the initial survey could have produced a more varied sample. The majority of participating families were all White middle-class families who were well-educated. While there was one participant who identified as Asian, having a sample that drew from a broader range of different cultural backgrounds would have produced different perspectives. Differing socioeconomic backgrounds would have also broadened the scope of the study.

The study was completed with two distinct groups of participants. Data from the initial group of five participants were coded using open and axial coding. As codes had already been established when the second group of five participants was added, they were coded using deductive coding as there was no way to remove all knowledge of the first set of codes. While all possible steps were taken to ensure this did not create a bias, it did present a limitation within the study.

This study focused on families of students with low vision who demonstrated high levels of resiliency. Future studies could look at the families of students who are blind and demonstrate high levels of resiliency to allow comparisons between the two groups. It would be equally important to study those families within both the low vision and blind groups who demonstrated low levels of resiliency and compare differences between which risk factors and protective factors were at play when resiliency was low versus when it was high. A larger quantitative study that compared the level of resiliency within families of students who are blind with those who have low vision would be interesting as well. To further tease out those differences, the quantitative piece could be followed with interviews of random participants to further explore the differences that existed. Another consideration for future studies would be the inclusion of a diverse ethnic and socioeconomic group of participants.

While resiliency cannot be taught because it must be earned through experiencing hard things and moving past them in a positive way, programs have been developed in other areas that look at providing families with the ability to strengthen their protective factors to be more prepared for their next adversity. Further research could be done on supplying families with children with visual impairments the services and training provided within those programs to determine their effectiveness with this population. This would allow eye care professionals, teachers of the visually impaired, as well as other professionals involved with this population to better serve them and help to increase positive outcomes for the children involved.

## Conclusion

The presence of resiliency implies that families have been faced with adversity and utilizing their strengths and resources they have moved through the dynamic process that allowed them to rebound from that crisis or struggle and move forward in a positive direction. The families within this study all had the common characteristic of including a child with low vision within their family. From there, other common risk factors appeared to challenge them.

They faced unsupportive professionals, decreased trust in those professionals, the struggle to find a place to fit in amidst negative societal perceptions, and the uncertainty inherent in a diagnosis with many open-ended possibilities.

Families leaned into some common protective factors to assist them with moving forward positively. They were able to accept their child's visual impairment, focus on the positives in most every situation, and maintain an internal locus of control. Families sought out strong connections within their nuclear family as well as connecting with extended family and others who could relate to the presence of hard things in their children's lives. They made changes to their family communication and structure to better support each other and prioritized problem solving together. They became experts on their child's visual impairment, fierce advocates for their child, and sought out supportive professionals who could help them meet their goals.

As professionals in the field of visual impairment, these families could help us to understand how to better support those students we work with and their families. While we will not be able to apply what works for these families to every family we encounter, this provides a good knowledge base to begin the conversation with our families to help determine what will best support each family. Families' desire to have understanding, responsive, and flexible professional partners in their child's education could certainly be seen as a universal need. By striving to help families gain the knowledge they require while continuing to focus them in a positive direction, we can hopefully help them move closer to a higher level of resiliency and forge more positive outcomes for the students we serve.

# REFERENCES

Allred, K. W. (2015). Engaging parents of students with disabilities: Moving beyond the grief model. *Improving Schools, 18*(1), 46-55.

American Psychological Association. (n.d.). *Diathesis-stress model*. https://dictionary.apa.org/diathesis-stress-model

Anthony, E. J. (1987). Risk, vulnerability and resilience: An overview. In E. J. Anthony & B. J. Cohler (Eds.), *The invulnerable child* (pp. 3-48). The Guilford Press.

Anthony, E. J., & Cohler, B. J. (Eds.). (1987). *The invulnerable child.* The Guilford Press.

Armstrong, M. I., Birnie-Lefcovitch, S., & Unger, M. T. (2005). Pathways between social support, family well being, quality of parenting, and child resilience: What we know. *Journal of Child and Family Studies 14*(2*),* 269-281.

Bambara, J. K., Wadley, V., Owsley, C., Martin, R. C., Porter, C., & Dreer, L. E. (2009). Family functioning and low vision: A systematic review. *Journal of Visual Impairment & Blindness, 103*(3), 137-149.

Barrett, J. R. (2007). The researcher as instrument: Learning to conduct qualitative research through analyzing and interpreting a choral rehearsal. *Music Education Research, 9*(3), 417-433.

Bayrakli, H., & Kaner, S. (2012). Investigating the factors affecting resiliency in mothers of children with and without intellectual disability. *Educational Sciences: Theory & Practice, 12*(2), 936-943.

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. (2012). Resilience in family members of persons with autism spectrum disorder: a review of the literature. *Issues in Mental Health Nursing, 33*(10), 650-656.

Biopsychosocial model. (n.d.). *Physiopedia*. https://www.physio-pedia.com/Biopsychosocial_Model

Bitsika, V., Sharpley, C. F., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental and Physical Disabilities, 25*(5), 533-543. https://doi.org/10.1007/s10882-013-9333-5

Bonanno, G. A. (2004). Loss, trauma, and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *The American Psychologist, 59*(1), 20-28. https://doi.org/10.1037/0003-066X.59.1.20

Broderick, C. B. (1993). *Understanding family process basics of family systems theory*. Sage Publications.

Centers for Disease Control and Prevention. (n.d.). *Fast facts of common eye disorders*. https://www.cdc.gov/visionhealth/basics/ced/fastfacts.htm#:~:text=Approximately%206.8%25%20of%20children%20younger,wearing%20glasses%20or%20contact%20lenses.

Chan, F., Da Silva Cardoso, E., & Chronister, J. A. (Eds.). (2009). *Understanding psychosocial adjustment to chronic illness and disability*. Springer.

Cohler, B. J. (1987). Adversity, resilience, and the study of lives. In E. J. Anthony & B. J. Cohler (Eds.), *The invulnerable child* (pp. 363-406). The Guilford Press.

Cramm, J. M., & Nieboer, A. P. (2011). Psychological well-being of caregivers of children with intellectual disabilities: Using parental stress as a mediating factor. *Journal of Intellectual Disabilities 15*(2), 101-113.

Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry & research design: Choosing among five approaches.* Sage Publications.

Crowther, S., Ironside, P., Spence, D., & Smythe, L. (2017). Crafting stories in hermeneutic phenomenology research: A methodological device. *Qualitative Health Research 27*(6), 826-835.

De Klerk, H., & Greeff, A. P. (2011). Resilience in parents of young adults with visual impairments. *Journal of Visual Impairment & Blindness, 105*(7), 414-424.

Duncan, J. M., Garrison, M. E., & Killian, T. S. (2021). Measuring family resilience: Evaluating the Walsh Family Resiliency Questionnaire. *The Family Journal: Counseling and Therapy for Couples and Families, 29*(1), 80-85.

Emiliussen, J., Engelsen, S., Christiansen, R., & Harnow Klausen, S. (2021). We are all in it!: Phenomenological qualitative research and embeddedness. *International Journal of Qualitative Methods, 20,* 1-6

Finlay, L. (2009). Exploring lived experience: Principles and practice of phenomenological research. *International Journal of Therapy and Rehabilitation, 16*(9), 474-481.

Fleming, J., & Ledogar, R. J. (2008). Resilience, an evolving concept: A review of literature relevant to aboriginal research. *Canadian Institute of Health Research, 6*(2), 7-23.

Fletcher, D., & Sarkar, M. (2013). Psychological resilience: A review and critique of definitions, concepts, and theory. *European Psychologist 18*(1), 12-23.

Good Reads. (2023). *Helen Keller quotes.* https://www.goodreads.com/quotes/4811-character-cannot-be-developed-in-ease-and-quiet-only-through

Greeff, A. P., & Nolting, C. (2013). Resilience in families of children with developmental disabilities. *Families Systems & Health, 31*(4), 396-405. https://doi.org/10.1037/a0035059

Greeff, A. P., & Van Der Walt, K. J. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disability, 45*(3), 347-355.

Greeff, A. P., Vansteenwegen, A., & Gillard, J. (2012). Resilience in families living with a child with a physical disability. *Rehabilitation Nursing, 37*(3), 97-104. https://doi.org/10.1002/RNJ.00018

Guo, T., & Spina, R. (2019). Cross-cultural variations in extreme rejecting and extreme affirming response styles. *Journal of Cross-Cultural Psychology 50*(8), 955-971.

Hadfield, K., & Unger, M. (2018). Family resilience: Emerging trends in theory and practice. *Journal of Family Social Work, 21*(2), 81-84.

Halstead, E., Ekas, N., Hastings, R. P., & Griffith, G. M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders, 48*, 1108-1121. https://doi.org/10.1007/s10803-017-344-z

Hayman, B., Wilkes, L., & Jackson, D. (2012). Journaling: Identification of challenges and reflection on strategies. *Nurse Researcher, 19*(3), 27-31.

Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities 14*(2), 159-171.

Hickey, E. J., Stransky, M., Kuhn, J., Rosenberg, J. E., Cabral, H. J., Weitzman, C., Broder-Fingert, S., & Feinberg, E. (2021). Parent stress and coping trajectories in Hispanic and non-Hispanic families of children at risk of autism spectrum disorder. *Autism, 25*(6), 1694-1708.

Individuals With Disabilities Education Act § 300.8 (2004). https://sites.ed.gov/idea/regs/b/a/300.8

Jessup, G. M., Cornell, E., & Bundy, A. C. (2019). The treasure in leisure activities: Fostering resilience in young people who are blind. *Journal of Visual Impairment & Blindness, 104*(7), 419-430. Doi:10.1177/0145482x1010400705

Khanlou, N., & Wray, R. (2014). A whole community approach toward child and youth resilience promotion: A review of resilience literature. *International Journal of Mental Health Addiction, 12*, 64-79.

Lavee, Y., McCubbins, H. I., & Patterson, J. M. (1985). The double ABCX model of family stress and adaptation: An empirical test by analysis of structural equations with latent variables. *Journal of Marriage and the Family, 47*(4), 811-825.

Laverty, S. M. (2003). Hermeneutic phenomenology and phenomenology: A comparison of historical and methodological considerations. *International Institute for Qualitative Methods, 2*(3), 21-35.

Leyser, Y., Heinze, A., & Kapperman, G. (1996). Stress and adaptation in families of children with visual disabilities. *Families in Society, 77*(4), 240-249.

Lupon, M., Armayones, M., & Cardona, G. (2018). Quality of life among parents of children with visual impairment: A literature review. *Research in Developmental Disabilities, 83,* 120-131.

Mackay, R. (2003). Family resilience and good child outcomes: An overview of the research literature. *Social Policy Journal of New Zealand, 20,* 98-118.

MacLeod, K., Causton, J. N., Radel, M., & Radel, P. (2017). Rethinking the individualized education plan process: Voices from the other side of the table. *Disability & Society, 32*(3), 381-400.

Masten, A. S. (2018). Resilience theory and research on children and families: Past, present, and promise. *Journal of Family Theory & Review, 10*(1), 12-31. https://doi.org/10.1111/jftr.12255

Masten, A. S., & Monn, A. R. (2015). Child and family resilience: A call for integrated science, practice, and professional training. *Family Relations, 64,* 5-21.

McConnell, D., & Savage, A. (2015). Stress and resilience among families caring for children with intellectual disability: Expanding the research agenda. *Current Developmental Disorders Reports, 2*(2), 100-109.

McConnell, D., Savage, A., & Breitkreuz, R. (2014). Resilience in families raising children with disabilities and behavior problems. *Research in Developmental Disabilities, 35*(4), 833-848. https://doi.org/10.1016/j.ridd.2014.01.015

McCubbin, H. I., & McCubbin, M. A. (1988). Typologies of resilient families: Emerging roles of social class and ethnicity. *Family Relations*, *37*(3), 247-254. https://doi.org/10.2307/584557

Merriam, S. B., & Tisdell, E. J. (2016). *Qualitative research: A guide to design and implementation fourth edition*. Jossey-Bass.

Merriam-Webster. (2021). *Resiliency*. https://www.merriam-webster.com/dictionary/resiliency

Migerode, F., Maes, B., Buysse, A., & Brondeel, R. (2012). Quality of life in adolescents with a disability and their parents: The mediating role of social support and resilience. *Journal Developmental & Physical Disabilities, 24,* 487-503.

Muir, K., & Strnadova, I. (2014). Whose responsibility? Resilience in families of children with developmental disabilities. *Disability & Society, 29*(6), 922-937.

Peck, E. C. (1987). The traits of true invulnerability and posttraumatic stress in psychoanalyzed men of action. In E. J. Anthony & B. J. Cohler (Eds.), *The invulnerable child* (pp. 315-360). The Guilford Press.

Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: a review of key factors and recommendations for practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, *11*(2), 92-98.

Porcelli, P., Ungar, M., Liebenberg, L., & Trepanier, N. (2014). (Micro)mobility, disability and resilience exploring well-being among youth with physical disabilities. *Disability & Society, 29*(6), 863-876. Doi: 10.1080/09687599.2014.902360.

Quintero, F. J., Amaris, M. D. C., Villalba, K., & Pacheco, R. A. (2021). Family functioning and coping strategies in families of people with visual impairments. *British Journal of Visual Impairment, 41*(2), 1-12. Doi: 10.1177/02646196211036392

Richardson, G. E. (2002). The metatheory of resilience and resiliency. *Journal of Clinical Psychology, 58*(3), 307-321.

Sanderson, K. A. (2023). *Be prepared to fight like hell: Parent advice for IEP meetings*. https://doi.org/10.1080/09362835.2023.2184819

Sandler, I., Ingram, A., Wolehik, S., Tein, J., & Winslow, E. (2015). Long-term effects of parenting-focused preventive interventions to promote resilience of children and adolescents. *Child Development Perspectives, 9*(3), 164-171.

Slone, A., & Bowe, B. (2014). Phenomenology and hermeneutic phenomenology: The philosophy, the methodologies, and using hermeneutic phenomenology to investigate lecturer's experiences of curriculum design. *Qual Quant, 48,* 1291-1303.

Southwick, S. M., Bonanno, G. A., Masten, A. S., Panter-Brick, C., & Yehuda, R. (2014). Resilience definitions, theory, and challenges: Interdisciplinary perspective. *European Journal of Psychotraumatology, 5*(1), 25338-14. https://doi.org/10.3402/ejpt.v5.25338

Troster, H. (2001). Sources of stress in mothers of young children with visual impairments. *Journal of Visual Impairment and Blindness, 95*(10), 623-637.

Tuttle, D. W., & Tuttle, N. R. (2004). *Self-esteem and adjusting with blindness: The process of responding to life's demands* (3rd ed.). Charles C. Thomas Books.

Ulster, A. A., & Antle, B. J. (2005). In the darkness there can be light: A family's adaptation to a child's blindness. *Journal of Visual Impairment & Blindness, 99*(4), 209-218.

Ungar, M. (2006). Nurturing hidden resilience in at-risk youth in different cultures. *Journal Canadian Academic Child Adolescent Psychiatry, 15*(2), 53-58.

Ungar, M., Brown, M., Liebenberg, L., Othman, R., Kwong, W., Armstrong, M., & Gilgun, J. (2007). Unique pathways to resilience across cultures. *Adolescence, 42*(166), 287-310.

U.S. Department of Education. (2021). *43rd annual report to Congress on the implementation of the Individuals with Disabilities Education Act.* https://sites.ed.gov/idea/files/43rd-arc-for-idea.pdf

Walsh, F. (1996). The concept of family resilience: Crisis and challenge. *Family Process, 35,* 261-281.

Walsh, F. (2002). A family resilience framework: Innovative practice applications. *Family Relations*, *51*(2), 130-137. http://dx.doi.org/10.1111/j.1741-3729.2002.00130.x

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*(1), 1-18.

Walsh, F. (2016a). Family resilience: A developmental systems framework. *European Journal of Developmental Psychology*, *13*(3), 313-324.

Walsh, F. (2016b). *Strengthening family resilience* (3rd ed.). The Guilford Press.

Werner, E. E., & Smith, R. S. (2001). *Journeys from childhood to midlife: Risk, resilience, and recovery*. Cornell University Press.

Widyawati, Y., Scholte, R. H. J., Kleemans, T., & Otten, R. (2021). Positive parenting and its mediating role in the relationship between parental resilience and quality of life in children with developmental disabilities in Java Island, Indonesia. *Research in Developmental Disabilities, 112,* 103911.

Zegeye, T. G. (2019). An investigation on the status of resilience among blind adolescent students. *Journal of Pedagogical Research*, *3*(1), 50-59. https://doi.org/10.33902/JPR.2019.4

# APPENDIX A

# INSTITUTIONAL REVIEW BOARD APPROVAL

Date: 01/25/2023

Principal Investigator: Deborah Mendoza

Committee Action: IRB EXEMPT DETERMINATION –

New Protocol Action Date: 01/25/2023

Protocol Number: 2212047164

Protocol Title: Resiliency in Families of Children with Visual Impairment - exempt review

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) 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). 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 Institutional Review Board (unco.edu)

Sincerely,

Nicole Morse Research

Compliance Manager

University of Northern Colorado: FWA00000784

# APPENDIX B

# RECRUITMENT ANNOUNCEMENT

Hi everyone,

I am a TVI/COMS in Adams 12 and I am hoping you can help me out. I am completing my final research for my PhD in Special Education and need your help with recruiting families to participate. I am looking at resiliency within families of children with visual impairment.

On your caseload do you have a family of a child with low vision who meets the following criteria:

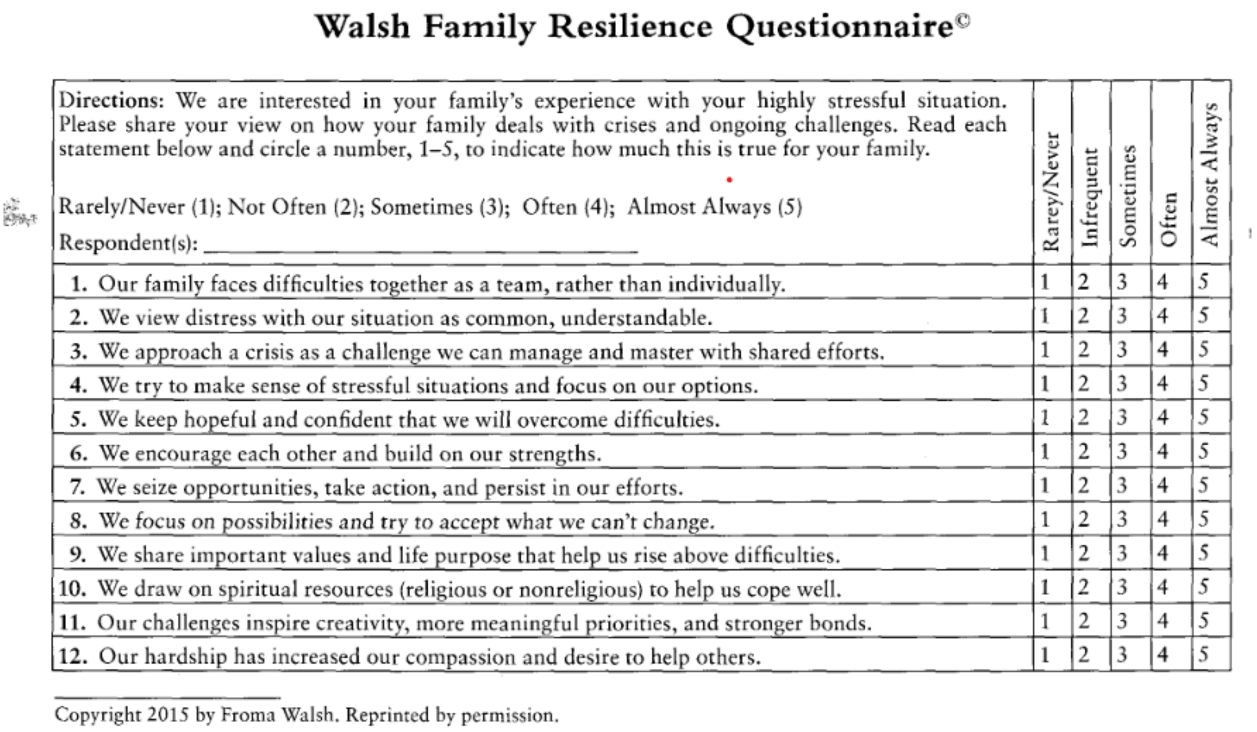
- They have fully accepted their child's visual impairment and embrace it
- They are active and positive participants in the IEP process
- They are involved in what you do with their child in a positive way
- They hold their child to the same standards as other children in their family
- They give them the same opportunities as other children in their family
- They make connections for their child other people with visual impairments

If so, I would love to invite them to be a part of my research study. I am hoping to gain more information on the risk factors that are involved for families of children with visual impairments and the protective factors that allow them to overcome that adversity to move forward in a positive direction. For this study, I am targeting families of children with low vision. The criteria I would like to use is something between: an acuity of no better than 20/70 in the better eye, a field restriction of 20 degrees or less, or a physical condition of the visual system, which cannot be medically corrected on one end of the continuum and dual readers on the other. If braille is their primary mode they would not work for this study. Families would be asked to complete a short questionnaire, a couple of interviews, and short journal responses. Please let me know if you have a family who would match this criterion and I will send you the link to the initial survey. Thank you!

Debbie Mendoza

# APPENDIX C

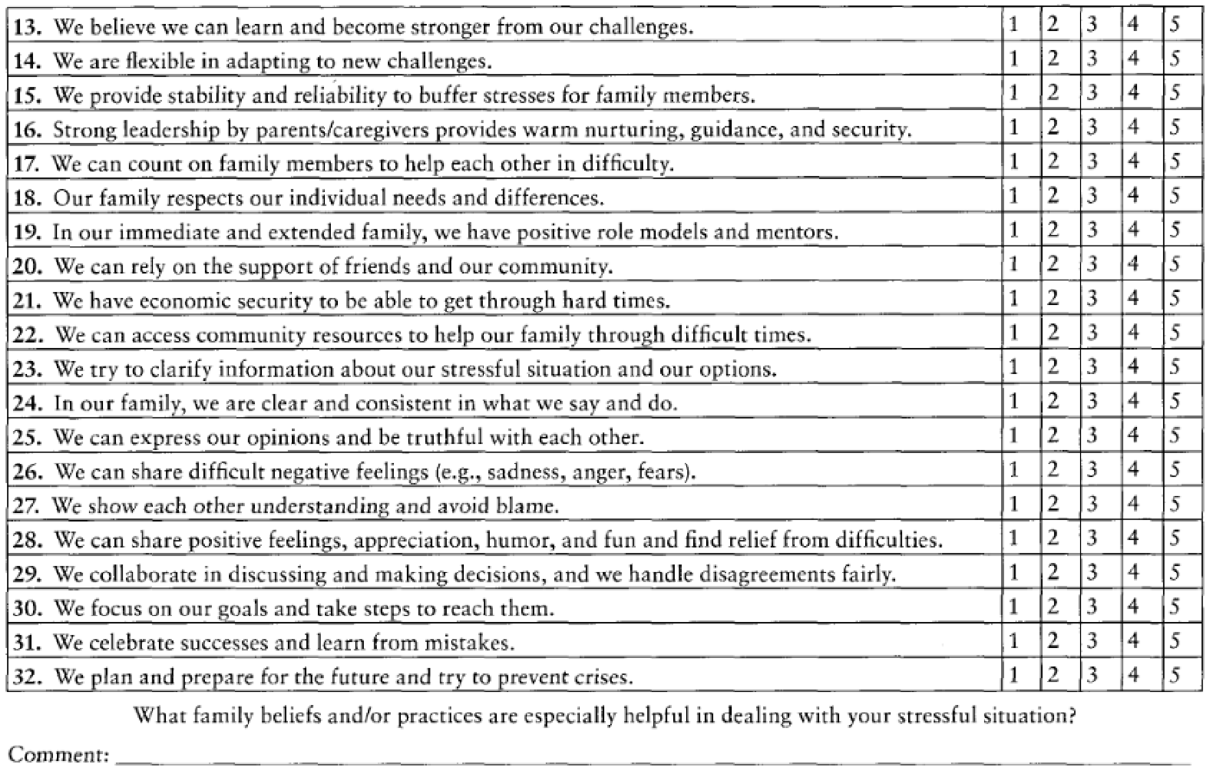
# THE WALSH FAMILY RESILIENCY QUESTIONNAIRE



## Walsh Family Resilience Questionnaire©

| Directions: We are interested in your family's experience with your highly stressful situation. Please share your view on how your family deals with crises and ongoing challenges. Read each statement below and circle a number, 1–5, to indicate how much this is true for your family.<br>Rarely/Never (1); Not Often (2); Sometimes (3); Often (4); Almost Always (5)<br>Respondent(s): ______________________ | Rarey/Never | Infrequent | Sometimes | Often | Almost Always |
|---|---|---|---|---|---|
| **1.** Our family faces difficulties together as a team, rather than individually. | 1 | 2 | 3 | 4 | 5 |
| **2.** We view distress with our situation as common, understandable. | 1 | 2 | 3 | 4 | 5 |
| **3.** We approach a crisis as a challenge we can manage and master with shared efforts. | 1 | 2 | 3 | 4 | 5 |
| **4.** We try to make sense of stressful situations and focus on our options. | 1 | 2 | 3 | 4 | 5 |
| **5.** We keep hopeful and confident that we will overcome difficulties. | 1 | 2 | 3 | 4 | 5 |
| **6.** We encourage each other and build on our strengths. | 1 | 2 | 3 | 4 | 5 |
| **7.** We seize opportunities, take action, and persist in our efforts. | 1 | 2 | 3 | 4 | 5 |
| **8.** We focus on possibilities and try to accept what we can't change. | 1 | 2 | 3 | 4 | 5 |
| **9.** We share important values and life purpose that help us rise above difficulties. | 1 | 2 | 3 | 4 | 5 |
| **10.** We draw on spiritual resources (religious or nonreligious) to help us cope well. | 1 | 2 | 3 | 4 | 5 |
| **11.** Our challenges inspire creativity, more meaningful priorities, and stronger bonds. | 1 | 2 | 3 | 4 | 5 |
| **12.** Our hardship has increased our compassion and desire to help others. | 1 | 2 | 3 | 4 | 5 |

---



| | | | | | |
|---|---|---|---|---|---|
| **13.** We believe we can learn and become stronger from our challenges. | 1 | 2 | 3 | 4 | 5 |
| **14.** We are flexible in adapting to new challenges. | 1 | 2 | 3 | 4 | 5 |
| **15.** We provide stability and reliability to buffer stresses for family members. | 1 | 2 | 3 | 4 | 5 |
| **16.** Strong leadership by parents/caregivers provides warm nurturing, guidance, and security. | 1 | 2 | 3 | 4 | 5 |
| **17.** We can count on family members to help each other in difficulty. | 1 | 2 | 3 | 4 | 5 |
| **18.** Our family respects our individual needs and differences. | 1 | 2 | 3 | 4 | 5 |
| **19.** In our immediate and extended family, we have positive role models and mentors. | 1 | 2 | 3 | 4 | 5 |
| **20.** We can rely on the support of friends and our community. | 1 | 2 | 3 | 4 | 5 |
| **21.** We have economic security to be able to get through hard times. | 1 | 2 | 3 | 4 | 5 |
| **22.** We can access community resources to help our family through difficult times. | 1 | 2 | 3 | 4 | 5 |
| **23.** We try to clarify information about our stressful situation and our options. | 1 | 2 | 3 | 4 | 5 |
| **24.** In our family, we are clear and consistent in what we say and do. | 1 | 2 | 3 | 4 | 5 |
| **25.** We can express our opinions and be truthful with each other. | 1 | 2 | 3 | 4 | 5 |
| **26.** We can share difficult negative feelings (e.g., sadness, anger, fears). | 1 | 2 | 3 | 4 | 5 |
| **27.** We show each other understanding and avoid blame. | 1 | 2 | 3 | 4 | 5 |
| **28.** We can share positive feelings, appreciation, humor, and fun and find relief from difficulties. | 1 | 2 | 3 | 4 | 5 |
| **29.** We collaborate in discussing and making decisions, and we handle disagreements fairly. | 1 | 2 | 3 | 4 | 5 |
| **30.** We focus on our goals and take steps to reach them. | 1 | 2 | 3 | 4 | 5 |
| **31.** We celebrate successes and learn from mistakes. | 1 | 2 | 3 | 4 | 5 |
| **32.** We plan and prepare for the future and try to prevent crises. | 1 | 2 | 3 | 4 | 5 |

What family beliefs and/or practices are especially helpful in dealing with your stressful situation?

Comment: ______________________________________________

(Dr. F. Walsh, personal communication, 10/29/22)

# APPENDIX D

# DEMOGRAPHIC QUESTIONNAIRE

Please provide the following background information about your child:

1. Age:
2. Gender:
3. What grade level is your child currently?
4. What is your child's eye condition?
5. Do they fit one of the following criteria?
    a. Acuity of no better than 20/70 in their better eye
    b. A visual field restriction of 20 degrees or less
    c. A physical condition of the visual system which cannot be medically corrected
6. At what age did they receive their visual diagnosis?
7. Does your child have an IEP or IFSP that includes services from a teacher of the visually impaired?
8. How many years has your child received special education services under a Visual Impairment label?
9. How many years have they attended public school?
10. Is your child currently receiving direct or consultative services form a certified teacher of the visually impaired?
11. Is your child currently receiving direct or consultative services from a certified orientation and mobility specialist?
12. Does your child have any other medical conditions?
    a. Yes
    b. no
13. If yes, please list the conditions:
14. Do you have any other children with disabilities?
15. Do you have primary custody of your child?

Information about you:

1. Gender:
2. Age (years)
    a. 18-25
    b. 26-35
    c. 36-45
    d. 46-55
    e. 56-65
    f. 66 or older
    g. Prefer not to answer
3. Married
    a. Yes
    b. No
4. Ethnicity
    a. African American
    b. Caucasian
    c. Latino/a

    d. Native American/Asian
    e. More than one
    f. Other
    g. Prefer not to answer

5. Highest level of education
    a. High school/associate's
    b. Bachelor's
    c. Master's
    d. Doctorate
    e. Alternative certificate
    f. Prefer not to answer
6. Geographic Area
    a. Urban
    b. Rural
    c. Suburban
    d. Prefer not to answer

# APPENDIX E

# APPROVAL LETTER FOR QUESTIONNAIRE USE

**From:** Froma Walsh <fwalsh@uchicago.edu>
**Sent:** Saturday, October 29, 2022 1:35 PM
**To:** Mendoza, Deborah <mend7547@bears.unco.edu>
**Subject:** Re: Please Help dissertation research

Dear Debbie,

I am glad to hear of your interest in family resilience. Attached please find the WFRQ scale and accompanying material.

The items are simply summed and not weighted.

Kindly contact me with any questions or concerns and inform me of your study findings and any report or publication for our international log.

With best wishes for your research,
Froma Walsh

Froma Walsh, PhD
Co-Director, Chicago Center for Family Health
Mose & Sylvia Firestone Professor Emerita
The University of Chicago
fwalsh@uchicago.edu
www.ccfhchicago.org
Author, Strengthening Family Resilience 3e, Guilford Press

# APPENDIX F

# INTERVIEW QUESTIONS

Questions for first parent interviews:

1. Tell me about your family.
    a. How involved is your extended family?
    b. How accepting are they of your child's visual impairment?
2. Tell me a little about your child's visual impairment.
    a. How old were they when they received their diagnosis?
    b. How well have they adapted to their visual impairment?
    c. How do you feel about your child's visual impairment?
3. When you think back to when you learned about your child's visual impairment, what family beliefs and/or practices were especially helpful in dealing with the diagnosis?
4. How has your family changed as a result of the visual impairment? Please provide examples.
5. To what extent have your child and your family defined by their visual impairment? Do you feel that you control the visual impairment, or does it control you? How so?
6. What types of support have you received from outside of your immediate family? Please describe.
7. Which of those supports were the most helpful? Why
8. Which were least helpful? Why?
9. What goals do you have as a family?
10. As a family how do you generally approach challenges?
11. Tell me about challenges that you may have faced/experienced as a family. Please share or provide an example about a time or an experience that was challenging to your family.

12. When you think about highly stressful times within your family, how do you communicate with each other? Please provide an example of a stressful time and how you communicated with each other.
13. To what extent do you feel that you can have open and honest communication with each other around your feelings?
14. What is important to your family when you problem solve challenging situations?
15. Would you say that as a family it is easier to find the positives in a situation or the challenges? How so? Why?
16. When you think about stressful situations your family has been in, are there any other things we have not talked about yet that you feel have made the situation more stressful?
17. What other things we have not talked about have been helpful for your family during stressful times?
18. Is there anything else you would like to share with me?
19. Do you have any questions for me?

Questions for second interviews:

For all participants:

1. As a family, how do you celebrate accomplishments?
2. What are some things you have put into place to take care of yourself in stressful situations? How do other members of your family make sure to care for themselves so that you can come back together as a whole family?
3. What are some examples of how your family has been flexible when dealing with challenging situations?

Participant 1:

1. You talked a little about pity you received from your family and not fitting in well with other VI parents. What has been your overall perception of how society as a whole receives your girls?
2. How did trust play into your need to become an expert on your girls' VI? How do you feel today? Is it easier to trust now?
3. What role do you feel like technology has played in this process for you?
4. What strategies have helped you to rally confront and deal with the uncertainty of your daughters' progression?

Participant 2:

1. I know that you talked about sometimes having negative reactions when you and your daughter go out into the community, have you had any other experiences with how society perceives your daughter?
2. You talked about your divorce being a positive self-care piece for you. Are there any other things you do to make sure you are in a positive place for your family?
3. Can you talk to me about the trust or lack of trust you have in the professionals that work with your daughter? How does that play into your need to become an expert on your daughter's VI?
4. You talked about seeking out ForSight for your daughter so that she had a connection to others with VI. Did you ever seek out support groups for yourself?

Participant 3:

1. You talked a lot about support you have received from different professionals. Were there any instances where professionals were less than supportive?

2. How have society's perceptions of VI impacted you and your family?
3. Can you tell me a little more about your need to gather information about your daughter's VI? How did that need for more information play into your decision to become a TVI?
4. You talked a little about Anchor and how it was a little difficult to get there. Do you feel that it was beneficial for your daughter when you did make it there? How was the experience for you?

Participant 4:

1. Can you talk to me about the level of trust you had in the professionals who worked with your daughter?
2. What kind of role did technology play in your journey with your daughter?
3. How do you feel that you and your daughter fit into the world of VI?
4. How have society's perceptions of VI impacted you and your family?
5. Was there ever a time where you felt the need to become an expert on your daughter's VI?
6. How did you and your husband's relationship change to better support each other and your daughter after her diagnosis?

Participant 5:

1. How has your daughter's VI intensified the affects of her CP?
2. How have society's perceptions of VI impacted you and your family?
3. How did trust play into the interactions you had with the professionals you met for your daughter?
4. How did technology play into your journey?

Participant 6:

1. Can you tell me a little more about the problem solving processes your family goes through and the different pieces you find to be important?
2. How did technology play into your journey?
3. How have you had to change your communication style within your family to better support each other?
4. What does trust in the professionals around you mean to you?

Participant 7:

1. How have you connected your son with others with visual impairments? What connections have you made yourself with other parents of children with low vision?
2. It can be a little unsettling not knowing what to expect with a diagnosis of low vision, how have you dealt with that with your son?
3. You spoke a little about really seeking out more information about your child's condition and advocating with professionals in his world. Can you tell me a little more about what that looks like for you?
4. How does trust play into things when you look at interaction with others around your child's visual impairment?

Participant 8:

1. You mentioned that there were some things that your extended family just didn't understand because they aren't around all the time. Can you expand on that?
2. How does trust play into your relationship with the professionals in your son's world?

3. You talked about how when your son was born you immediately started looking for connections and resources. Can you tell me a little bit more about how you combatted the uncertainty that can come with a low vision diagnosis?
4. How has having your son changed your advocacy skills? How do you approach advocating with professionals?

Participant 9:

1. How does trust play into your relationship with the professionals in your son's life? What does trust look like for you?
2. You talked about how one of the TVIs your son had was not as supportive, how did you and your family move through that?
3. You talked about how your son worked at advocating for himself, how have your advocacy skills changed since having him?
4. Do you feel like you and your husband have had to change your relationship since having your son?
5. A diagnosis of low vision can come with a lot of uncertainty, you talked about how your renter really helped you to move through that, were there any other pieces that were instrumental in you being able to move forward positively?

Participant 10:

1. Can you tell me about connections you and your family have made with other families of kids with low vision? Or with other disabilities?
2. Having a diagnosis like your daughter's can come with a lot of uncertainty. I know that it has been awhile since you started to deal with that and it has just become a part of who

you are, but can you tell me about what helps you to face that uncertainty and move forward?

3. When you are out in the community with your daughter, can you tell me about the different reactions you get from members of the community?
4. How has your ability to advocate for your daughter changed over time?

# APPENDIX G

# JOURNAL QUESTIONS FOR PARENTS

1. Overall, when you are thinking about situations that challenge your family, what has made your family most successful in overcoming them?
2. What supports would you suggest other families seek out when they first receive a diagnosis of visual impairment for their child?
3. What else would you like me to know about anything we have talked about so far?

# APPENDIX H

# INFORMED CONSENT

UNIVERSITY OF
NORTHERN COLORADO

## CONSENT FORM FOR HUMAN PARTICIPANTS IN RESEARCH

**Study Title:** Family resilience in families of children with visual impairments

**Researcher:** Debbie Mendoza, Doctoral Student; mend7547@bears.unco.edu

**Research Advisor:** Silvia Correa-Torres, Ed.D., email: silvia.correa-torres@unco.edu

**Purpose and Background**: The purpose of this study is to understand the approach of families of children with visual impairments when presented with adversity, including receiving the original diagnosis of visual impairment. Of particular interest is determining which factors are more or less supportive in dealing with adverse situations. There is very little current research focusing specifically on families of children with visual impairments. Potential benefits of this research: a) development of different approaches to family support b) better understanding of factors that are beneficial to families and those that are detrimental

If you agree to participate in this research study, the following will occur:

- You will be asked to complete a demographic questionnaire. Completing the questionnaire will not take longer than 15-20 minutes.
- You will be asked to participate in a set of two interviews. Interviews will be conducted over a video conferencing platform to gather information about stressful situations your family has faced and strategies your family used within those situations. Interviews will last from 60-90 minutes and will be recorded to allow for transcribing what is said.

- Following the initial interview, you will be asked to journal on questions specific to your family’s response to stressors. Completing the journal will not take longer than 30 minutes.

**Confidentiality:** Your interview and journal responses will only be shared with members of the investigation team. By participating in this study, you have given us permission to release information to these persons. Although confidentiality cannot be guaranteed, every effort will be made to maintain your confidentiality. The confidentiality of participants will be ensured through the use of pseudonyms. Signed consents will be kept locked in the research advisor's office for three years.

**Risks:** Foreseeable risks are not greater than those that might be encountered when discussing a stressful situation with peers. If emotional distress occurs, you may contact 211 either by calling the number or going to the following website: https://www.211.org/get-help/mental-health to be connected to someone who can assist you with finding more long-term support.

__________ (Participant’s Initials)

**Benefits:** The proposed research could provide a better understanding of how to best support families of children with visual impairments as the deal with adverse situations.

**Costs:** The cost of participating in this study is the time invested to participate in the interview and journaling processes. No compensation will be provided to you for participating in this study.

**Questions:** If you have any questions about the study, you may contact the researcher. You may also contact the researcher’s advisor, Dr. Silvia Correa-Torres by email.

**Participation is voluntary.** You may decide not to participate in this study and if you begin participation, you may still decide to stop and withdraw at any time. Your decision will be respected and will not result in loss of benefits to which you are otherwise entitled. Having read the above and having had an opportunity to ask any questions, please sign below if you would like to participate in this research. A copy of this form will be given to you to retain for future reference. If you have any concerns about your selection or treatment as a research participant, please contact the IRB Administrator at: Office of Sponsored Programs, 25 Kepner Hall, University of Northern Colorado Greeley, CO 80639; 970-351-1910.

Participant's Signature ________________________________________Date___________

Researcher's Signature ________________________________________Date___________