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How Do Adults Who Are Blind Describe Their Quality of Life?

Loreta Dylgjeri

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HOW DO ADULTS WHO ARE BLIND DESCRIBE THEIR QUALITY OF LIFE?

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DEDICATION

To Miss. Casey, Cindy, Tony, and Marty for inspiring my research and encouraging
students who blind and visually impaired to have a life of quality!

To mom, in Heaven, I did it!

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To all the individuals who agreed to participate in my study, I can't mention you by name, but I am very grateful for participating in my research and sharing your life experiences with me. Thank you for inviting me to your homes and for many hours of conversations!

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ABSTRACT

This phenomenological study aimed to understand the Quality of Life (QOL) of six adults who are blind in the communities where they live or work. QOL is a construct that attempts to define what it means to “live the good life” (Schalock & Verdugo, 2002). To understand how individuals who are blind describe their QOL, we need a thorough understanding of how they describe their QOL based on their own lived experiences, beliefs, understandings, and attitudes towards the QOL. This study used a phenomenology method and was theoretically based on the QOL theory and its core domains and indicators, as identified by Schalock and Verdugo (2002). The study builds on previous research in blindness and QOL. Data was collected through interviews, field notes observations, documentation of demographic information, and the etiology of each participant’s visual impairment. The research question “How do adults who are blind describe their QOL?” was answered by participants’ significant and meaningful lived experiences of QOL that they shared in their interviews. The common themes that were identified through the analysis of data were (a) support from their families, (b) participants’ self-advocacy, self-motivation, and self-determination, (c) education and reading and writing Braille, (d) teachers of visually impaired and blind (TVI) and orientation and mobility (O&M) training, (e) independence, (f) support systems, (g)

education community about blindness, (j) transportation, (k) learning as adults, (l) services in the community, and (k) voting. Results and findings of the study demonstrate areas that affect the QOL for adults who are blind.

TABLE OF CONTENTS

Dedication.....	iii
Acknowledgements	iv
Abstract.....	vi
Table of Contents.....	viii
List of Tables	xi
List of Abbreviations	xi
Chapter One: Introduction	1
Chapter Two: Review of Literature.....	12
2.1 Definition of VI, Etiology, and Incidence	12
2.2 History of the Education of Children who are Blind and Visually Impaired.....	13
2.3 Educational measurements	20
2.4 Quality of Life (QOL) Framework	21
2.5 Qualitative and Quantitative Studies	26
2.6 Personal Development Domain	32
2.7 Self-Determination Domain	36
2.8 Interpersonal Relations Domain	38
2.9 Social Inclusion Domain	42
2.10 Rights Domain.....	47
2.11 Emotional Well-Being Domain	47

2.12 Physical Well-Being Domain	49
2.13 Material Well-Being Domain	52
Chapter Three: Methodology.....	58
3.1 Theoretical Approach	60
3.2 Phenomenology	63
3.3 Research Site	71
3.4 Pilot Study	71
3.5 The Individual Demographic Questionnaire	73
3.6 QOL Interview Questionnaire	75
3.7 Participants Selection	82
3.8 Data Collection	84
3.9 Data Analysis.....	87
3.10 Participants Demographic Information	87
3.11 Looking for Themes	92
Chapter Four: Results	96
4.1 Independence Factor.....	96
4.2 Social Participation Factor.....	127
4.3 Well-Being Factor	162
4.4 Unanticipated Findings.....	174
Chapter Five: Discussion.....	179
5.1 Risks and Benefits	184
5.2 Limitations and Considerations	184
5.3 Significance and Contributions	185

5.4 My Own Subjectivity and Positionality.....	186
5.5 Ethical Issues	188
5.6 Implications for Further Research	189
5.7 Researcher Role.....	190
References	191
Appendix A: Definition of Terms	199
Appendix B: TapeAcall	201
Appendix C: Invitation to Join the Study	202
Appendix D: Consent to be a Research Subject	204

LIST OF TABLES

Table 2.1 SCSDB School for the Blind 1864 Curriculum	14
Table 2.2 National Agenda Goals.....	18
Table 2.3 QOL Factors, Domains, and Indicators	23
Table 2.4 Personal Development Domain.....	33
Table 2.5 Self-Determination Domain	36
Table 2.6 Interpersonal Relations Domain.....	39
Table 2.7 Social Inclusion Domain	43
Table 2.8 Emotional Well-Being Domain.....	48
Table 2.9 Physical Well-Being Domain.....	50
Table 2.10 Material Well-Being Domain.....	53
Table 3.1 The Individual Demographic Questionnaire	73
Table 3.2 The Individual Demographic Questionnaire (Revised).....	75
Table 3.3 QOL Interview Questionnaire	76
Table 3.4 QOL Interview Questionnaire (Revised)	81
Table 3.5 Demographic Table	90
Table 3.6 Steve's Interview	92
Table 3.7 List of the Themes.....	94

LIST OF ABBREVIATIONS

APH	American Printing House for the Blind
ECC	Expanded Core Curriculum
COVID-19	The Coronavirus Disease 2019
IEP	Individualized Education Program
ILS	Independent Living Skills
IRB.....	Institutional Review Board
QOL	Quality of Life
NFB	National Federation for the Blind
SCSDB.....	South Carolina School for the Deaf and the Blind
O&M	Orientation and Mobility
TVI	Teacher of Visually Impaired and Blind
VI.....	Visual Impairment/Visually Impaired

CHAPTER ONE

INTRODUCTION

Definition and Etiology of Blindness

Blindness is defined as a significant vision loss which results in the inability to see anything with either eye or to discern light from darkness, even when wearing glasses or contact lenses with the best eye correction (National Federation of the Blind (NFB); The United States Census Bureau and the American Federation for the Blind (AFB), 2019). The population of individuals who are blind in the United States is relatively small. According to the American Printing House for the Blind (APH), the total number of legally blind children (ages five to twenty-one) enrolled in elementary and high schools in the USA as of December 2017 was 63,357. The number of students who were blind and attended public schools in 2019, was 53,155, which represents 83.9% of all children who were blind in the United States. The number of students who attended residential schools was 4,940 or 7.8% of all children who were blind (Federal Department of Education, 2019).

According to the data from the National Health Interview Survey (NHIS), the number of adults who have vision loss in the USA is estimated to be 21 million (Center for Disease Control, 2014), and 14.2% of the population with vision loss are blind (Guerrette & Smedema, 2005). Several factors can cause vision loss and blindness

including genetic causes, environmental causes, or accidents. The top five eye conditions that cause blindness in children and adults are cataract, age-related macular degeneration, diabetic retinopathy, and retinitis pigmentosa (www.blindinc.org). It is critical to look at the history of the education of children who are visually impaired and blind because the way we approach the education and development of children will depend on what we believe about blindness and what people who are blind can achieve (Castellano & Kosman, 1997).

History of Education of Children who are Blind

The education of children who are blind has a rich history beginning in the early 1880s with the establishment of the residential schools for the blind. The belief underlying these early schools was that children who were blind were capable individuals who could become contributing members of society (McMahon, 2014). According to Ferrell (2007), schools for the blind were affirmations of the potential of children who were blind, and education in a residential school was considered to be an investment in the child's future. In 1975, the Education for All Handicapped Children Act (EAHCA) ensured the access of the students with disabilities in public schools, giving their parents and guardians the option of educating students with disabilities close to home.

Within the next decade, the EAHCA was amended a number of times. In 1990, the EAHCA was renamed as the Individuals with Disabilities Education Act (IDEA). In 2004 the IDEA was reauthorized and amended in the Individuals with Disabilities Improvement Act. According to the IDEA the purpose of the law was to ensure that all children with disabilities have available to them a free and appropriate public education that emphasizes special and related services designed to meet their unique needs and

prepare them for further education, employment, and independent living (IDEA, 20 U.S.C. 1401 § [d][1][A], 2004).

After the EAHCA was signed into law in 1975, school districts were legally required to maintain or be able to access a continuum of alternative service delivery (from the least restrictive environment to the most restrictive environment) to ensure that students with disabilities could be educated in settings appropriate to their needs (McMahon & Sacks, 2014). This continuum has been a source of debate between proponents of the continuum, who maintained it is most important that students be educated in settings appropriate to an individual student's needs and proponents of the inclusion who maintain that students with disabilities should always be educated in general education settings alongside with students without disabilities. The various placement choices of educational placement in the continuum and the ensuing debate continue, although the continuum of alternative placement is still the law. The goals for educating children who are blind have changed from inclusion in the residential schools, which were envied for their quality of education (Ferrell, 2007) to inclusion in the public-school settings and the general curriculum.

Educational Goals and Measurement of Outcomes

The educational goals of children who are blind or visually impaired (VI) are measured through their Individuals Educational Progress (IEPs) and reported through the District School Report Cards and Accountability Reports (www.ed.sc.gov). According to these reports, the outcomes of these children are typically measured through academic achievement, test scores, graduation rates, overall student performance, and placement after graduation.

Schalock and his colleagues asserted that such quantitative measures are insufficient for measuring the success of all high school graduates, including those who are blind (Schalock & Verdugo, 2002; Schalock, 2004; Schalock, 2007). These authors recommended that qualitative measurements of success through the QOL theory be included in examinations of childrens' progress. Doing so adds direction, meaning, and validity to achievement outcomes. In the 1980s, the concept of the QOL was embraced as it captured a new and changing concept for individuals with disabilities (Schalock, 2011; Schalock & Verdugo, 2002). Since then, the QOL focus and application has expanded to include research in the fields of education, special education, health care (physical and behavioral), social services (disabilities and aging) and families (Schalock, 2004). Verdugo et al. (2005) supported this growing interest in determining the extent to which programs and service treatments improve the QOL for individuals with disabilities. Although few studies have been conducted investigating QOL in special education and other fields, virtually none have investigated the QOL of adults who are blind. Furthermore, the studies in the available literature for children and adults who are blind or VI only address individual aspects of QOL such as (a) system of supports, (b) transportation, (c) social experiences, (d) social network, and (e) employers' attitudes. We know little about the QOL of adults who are blind, and we need to understand better how adults who are blind describe their QOL based on their own lived experiences.

Research Question

The research question for the study was outlined and conceptualized according to the review of the extant literature in the field of blindness and VI, QOL theory, and the researcher's professional experience as a Teacher of Visually Impaired and Blind (TVI).

The research question for the study was: **How do adults who are blind describe their QOL?** My review of available research, coupled with my professional and educational experiences, led me to theorize that in addition to the educational placement settings and support systems, QOL domains and indicators play an essential role in determining how adults who are blind describe their QOL from their own perspectives. To understand how educational placement, support systems, and measurement of outcomes affect QOL, I completed a qualitative study which gave six adults who are blind the opportunity to describe their lived experiences.

Definition of QOL

The QOL concept is dynamic in nature and diverse in its associations (Schalock, 1994; Schalock & Verdugo, 2002). As such, QOL can be defined as individuals' perceptions of their positions in life in the context of the culture and value systems, goals, expectations, standards, and concerns in which they live (World Health Organization QOL Group, 1995). In 1995, Felce and Perry suggested the definition of QOL as general well-being influenced by objective circumstances and subjective perceptions across a variety of life domain issues. Schalock (2004) further defined the QOL definition of [individual] quality of life as a multi-dimensional phenomenon composed of eight core domains that are influenced by personal characteristics and environmental factors. These eight core domains are the same for all people, although they may vary individually in relative value and importance. In this regard, the assessment of the quality of life domains are based on culturally sensitive indicators. The eight domains are Personal Development, Self-Determination, Interpersonal Relations, Social Inclusion, Rights, and Emotional, Physical, and Material Well-Being (see Table 2.3). Schalock (2011)

advocated that the eight-core domains are essential to the hopes and dreams of all persons and resonate with the desire that each person can live more independently.

QOL, in theory and practice, has been both challenging and productive. According to Schalock (2004), one of the challenges faced by the researchers involves overcoming the belief that an enhanced QOL is a realistic and obtainable goal for all people, including those with disabilities. A second challenge is measuring the statistical significance of QOL in a low-incidence population, such as blindness. Hatton (1998) identified a third challenge when he asserted that summarizing objective and subjective assessments of several QOL dimensions to produce a single score was a process fraught with difficulty. However, Hatton supported the idea that for services to be evaluated using a QOL framework, both objective and subjective aspects of QOL across a range of dimensions need to be considered.

Furthermore, QOL has brought significant changes to how the purposes, characteristics, responsibilities, and desired outcomes from health and human service programs are measured (Schalock & Verdugo, 2002). Schalock and Boham (2003) advocated those outcomes become person-referenced and valued and that people be considered as customers. Hatton (1998) tried to stimulate a debate about QOL as a concept and a method of practice. He suggested that scientists adopting the QOL approach and nonscientists interested in other forms of knowledge-gathering need to engage each other in debate, including those people with mental retardation who are the “objects,” “subjects,” or “participants” in such knowledge gathering. The changes and debates in the research field of the QOL have been productive and contributed in developing definitions, practices, and measurements of QOL.

QOL Framework

My study is theoretically based on the QOL theory and the core domains and its indicators, as identified by Schalock and Verdugo (2002). Also, my study is phenomenological research with a goal of understanding and interpreting the quality of life from their perspectives of individuals who are blind. According to Schalock and Verdugo (2002), when assessing QOL, we adopt the view that “all people share similar human experiences and every human being is entitled to live a good life within his or her society” (p. 283). My interactions and observations during the interviews and my interpretations were descriptive. My ontological belief tends to accompany interpretative traditions, and according to Glesne (2016), portrays a world in which reality is socially constructed, complex, and ever-changing.

My personal experiences inform my scholarly opinion as a certified vision teacher currently working in a residential, educational setting as the Admissions / Community Liaison. I have worked at the South Carolina School for the Deaf and the Blind (SCSDB) for 27 years. For the past eight years, I have been involved in the process of admitting new students to SCSDB. As a TVI, I do believe that all students who are blind can be educated and become successful members of our society. I also believe that I am morally obligated to assist parents and guardians, and professionals who serve them in making the best educational placement decisions for their children and students. For children and adults who are blind to become productive members of society, it is essential that TVIs, educators and professionals in the field of educating blind or VI students to understand the desired life outcomes from the adults’ perspectives. QOL factors, domains, and indicators are a response to these understandings (Schalock & Verdugo, 2002).

Purpose of the Study

The purpose of my phenomenological study is to understand the QOL of six adults who are blind at the communities where they work or live. As an abstract concept, QOL is best described by the individuals themselves. To understand how individuals who are blind describe their QOL, I conducted a qualitative study to describe the lived experiences, beliefs, understandings, and attitudes towards the QOL of adults who are blind. Data was collected in natural settings through interviews, field note observations, documentation of demographic information, and etiology of each participant VI. The interview questions are aligned with the eight-core domains of QOL: Personal Development, Self-Determination, Interpersonal Relations, Social Inclusion, Rights, and Emotional, Physical, and Material Well-Being (Schalock & Verdugo, 2002; Table 2.3). Data collected was analyzed, and patterns and themes were established. The final written report includes the voices of the participants, a description, and an interpretation of the QOL as understood by them, as well as my reflections on my subjectivity and positionality. My phenomenological study creates a blended story (Starks & Trinidad, 2017) that gives readers the feel what it is to have the experience. I looked for “commonalities among participants in addition to what is unique about each individual” (Joseph, 2010, p. 118). I wrote a story that captures the important elements of the QOL lived experiences of the adults who are blind.

This study is very personal for me because as the Admissions/Community Liaison at the SCSDB, I am often the first-person contact for parents/guardians/school personnel and communities in seeking education for their children. Considering the full continuum of placement options for a child who is blind or VI and its ensuing effect on their

children's QOL as adults, I carry a moral obligation to advise parents and professionals for the best educational placement. I undertook this study because I want to understand and qualitatively interpret how blind adults describe their quality of life in-depth. In this study, I investigated the QOL of adults who are blind, focusing mainly on how they describe their own QOL life experiences as outlined by Schalock's QOL domains theory.

Methodology

My study is a qualitative study in which I gave six adults who are blind the opportunity to answer the following research question: How do you describe your quality of life? I was interested only in adults who are blind and graduated from public school or residential school settings. This study included semi-structured interviews, observations, field notes, and documentation of the participants' etiology of their visual impairment. I conducted the interviews in four phases. First, I met individually with all the participants to establish a good rapport, explain the purpose of the study, their involvement and privacy, the interview questions, and how the results of the study will be used. I scheduled the interviews according to each participant's preferred location, and I provided transportation when was needed and accepted. Then, I used TapeAcall app to record and transcribe the participants' responses. During one-on-one, face-to-face interviews, I observed and wrote detailed field notes of the participants' body language, orientation and mobility skills, use of their white canes, and blindisms (stereotypical, mannerism, self-stimulating behaviors specific to some individuals who are blind or VI).

After all the data was collected, I analyzed it and reported my findings. I transcribed all the interviews, deeply immersed myself in the data via reading, re-reading, writing, and re-writing and analyzed the data using Interpretive Phenomenological

Analysis (IPA). Data analysis consisted of developing a set of descriptive comments from the interview transcripts. I identified key phrases, descriptions, themes, in participants' responses. In the next level, I revealed themes and patterns from the participants' responses and transcriptions. Themes and patterns were used to establish the experiences most frequently mentioned by participants in the study. I sought to find "commonalities among participants in addition to what was unique about each individual" (Joseph, 2010, p. 118), and captured the important elements of the lived experiences of the six adults who are blind. After conducting the qualitative analysis, I wrote the report and drew the conclusions relating to my research question.

Contributions

My study increases understanding of how adults who are blind describe their QOL through their lived experiences. To develop a good QOL in young adults and adults who are blind, it is essential for us as educators and professionals to understand their desired outcomes. My study serves as a platform for the participants to describe their QOL based on their perspectives and life experiences. By describing their QOL, the participants will help teachers and professionals in the field of VI better understand the educational support and outcomes that play a role in the lives of the students who are blind in becoming qualitatively successful adults. QOL research is one way to help us understand, as "outsiders," how adults who are blind describe their QOL as adults. Community services, families, teachers, social workers, guidance counselors need to consider QOL outcomes for their students and clients who are blind. The understanding of what adults who are blind believe is vital to their QOL will help parents, guardians, educators, and professionals who educate, work or serve children or students who are

blind. Additionally, the results and findings of this study will contribute to new knowledge regarding the QOL lived experiences of people who are blind and to QOL literature.

CHAPTER TWO

REVIEW OF LITERATURE

This study aims to understand and interpret how adults who are blind describe their QOL through their lived experiences. In this chapter, I describe the definitions in the continuum of VI categories and the rich history of the education of the children who are blind and VI in the United States. Additionally, I present how research defines and measures the QOL, emphasizing findings from the available literature regarding the QOL domain theory. Also, I include both qualitative and quantitative research studies that address QOL for children, adolescents, and adults who are blind or VI.

2.1 Definition of VI, Etiology, and Incidence

VI is defined as an individual's loss of vision, whose visual acuity is 20/70 in the better eye with correction or as a visual field loss of less than 20 degrees (National Federation of the Blind, 2019). It includes (a) Legally Blind: acuity 20/200 or a visual field of less than 20 degrees; (b) Light Perception only; or (c) Blindness: no light perception. The etiologies of VI include genetics, prematurity, medical conditions, accidental occurrences, and aging. According to Jackson et al. (1998), the prevalence of legal blindness (20/200) in the general population is about 1.5%, whereas, among persons 65 and older, it is estimated to be 5%. This increase is due primarily to a rise in adventitious sight loss (i.e., sight loss after birth) stemming from chronic conditions that affect the eyes (e.g., diabetes, glaucoma, and macular degeneration).

Approximately 14 million individuals aged 12 years or older have a visual impairment (Vitale, et. al., 2006). The focus of my study is adults with blindness, defined as “significant vision loss,” which results in the inability to see or discern light from darkness with the best eye correction (NFB, The United States Census Bureau, AFB, 2019). Also, the adults who will be part of the study received services under the IDEA. In the IDEA VI is characterizes as a low-incidence disability, meaning low incidence is:

any impairment for which a small number of personnel with highly specialized skills and knowledge are needed in order for children with that impairment to receive early intervention services or a free appropriate public education (IDEA, 20 U.S.C. § 1462[c][C][3]).

According to the U.S. Department of Education (2003) data, students with low-incidence disabilities tend to be educated outside the general classroom for part of their school day. The American Printing House for the Blind (APH), indicates that the total number of legally blind children (ages 5-21 years) enrolled in elementary and high schools in the United States as of December 2017 was 63,357. Of those, 7.8% attended residential schools with a total enrollment of 4,940 students (APH, 2017). Sensory disabilities, including blindness, were among the first of disabilities to be identified and supported with specialized pedagogy. The history of education for children who are visually impaired and blind in the United States paved the road for changes and outcomes for all children with disabilities.

2.2 History of the Education of Children who are Blind and VI

The education of children who are blind or VI and blind in the United States has a rich and inspiring history. Schools for the blind were established during the first half of the

19th century with the belief that children who were blind were capable individuals who could become contributing members of society (Ferrell, 2007). Residential or special schools for the blind in the United States were modeled after the boarding schools in Europe and represent one of the significant milestones in the education of children who are blind. Founded in 1849, the South Carolina School for the Deaf and the Blind (SCSDB) located in Spartanburg, South Carolina, was one of the first schools for the blind in the United States. The story of SCSDB is one of change, tradition, progress, and perseverance (Brasington, 1999). SCSDB has a unique heritage. Although founded as a private school in 1849, SCSDB soon earned respect and support of the state's legislature and became a state institution in 1855. Brasington (1999) noted that even in the early days, students were subject to the same academic curriculum standards used in their schools (see Table 2.1). The SCSDB School for the Blind curriculum during the school year of 1864 included:

Table 2.1 *SCSDB School for the Blind 1864 Curriculum*

Curriculum Subjects		
Orthography	Natural History	Philosophy
Reading	Familiar Science	Geography
Writing	Algebra	Biblical and General Literature
Mental and Written Arithmetic	Rhetoric	Broom Making
English Grammar	Ancient and Modern History	Boot and Shoe Making

In the course of the next 100 years, specialized or residential schools were established in many states (McMahon, 2014). According to Ferrell (2007), schools for the blind were affirmations of the potential of children who were blind or VI in a society that

had not yet come to adopt education as a social and political goal. Children who were blind were not excluded from education in the same manner that children with other disabilities were. Instead, educating them was considered an investment in the future. By the mid of the 20th century, residential schools for the blind in the United States were envied for the quality of education they provided. Furthermore, VI including blindness, was one of the first among disability groups to include its students in general education. In 1900, parents of children with VI in Chicago demanded their children be educated closer to home than in the residential school in the southern part of Illinois (Ajuwoe et al, 2015). Public school classes for students with VI began primarily in large cities, and by the 1930s, residential schools were “mainstreaming” secondary students in local high schools. Inclusion for students with VI started long before the 1975 implementation of EAHCA and the IDEA. By the mid 20th century, the residential schools for the blind in the United States were operated almost like private schools, envied for the quality of education that they provided. The majority of children who were blind or visually impaired attended specialized or residential schools.

By the 1950s, public schools began to accept and educate children who were visually impaired and blind alongside non-disabled peers. They provided support for these students using various models of delivery, such as itinerant, resource, or consultative (McMahon, 2014). During the early 1970s, the professionals in the field of VI began to recognize the importance of non-academic learning, especially skills and knowledge that students need to have to transition from living either in a residential school or home to living independently. In 1972, the state of California opened The Blind Adolescent Life Skills Center. The Life Skills Center is another milestone in the education of children and

young adults who were blind or VI. Twenty graduated youths with VI from all over California attended the center and were supported in their growth towards independence. The original curriculum included five objectives (a) Orientation and Mobility (O&M), (b) Vocational Skills, (c) Social skills, (d) Independent Living Skills (ILS), and (e) Recreation Skills. In 2002, Hatton wrote:

Some years after the Living Skills Center was founded, we began to hear the use of the word transition. The concept virtually paralleled the curriculum of the Living Skills Center. Fellow educators of the blind and visually impaired young people pioneered transition before it was ever a defined concept. They did so because they were sensitive to the needs of students and acted to meet their needs (p. 5).

Educational change was reflective of parental support and resulted in legislative action for change. The EAHCA significantly affected the provision of special education services to children, guaranteeing a free appropriate public education to all disabled children in the least restrictive environment. The days of soaring enrollments for specialized and residential schools for the blind were over. SCSDB Superintendent N. F. Walker wrote in the 1978 Annual Report:

The trend has already begun. It is impossible, at this time, to predict the extent to which the education of the handicapped can be successfully accomplished at the local school district. It is anticipated that our Multi-Handicapped School will grow in size during the next few years and, thus, perhaps be the major school on our campus (Brasington, 1999, p. 13).

During the 1990s, a proponents of a movement called the regular education initiative proposed to eliminate the continuum of placement options requirements in the law and place all students with disabilities in general education classes with support (McMahon & Sacks, 2014). Parents and professionals who served students with VI, including those who were blind, rejected this perspective, believing that due to the characteristics, the unique educational needs of students with VI, multiple models of service delivery were essential to providing these students the education they needed. As a result, in Fall 1993, the National Agenda for Educating Children and Youth with VI, including those with Additional Disabilities, was established. The primary goal of the National Agenda was to improve educational opportunities for children and youths who were blind or visually impaired to be equal to those received by their sighted peers. The National Agenda (AFB Press, 2015) aimed at achieving eight priority goals for improving the quality of educational services for children with VI and blindness, including those with additional disabilities (see Table 2.2).

Additionally, the National Agenda became a part of the development of new curricula called the Expanded Core Curriculum (ECC). Leaders in the field of blindness and VI hypothesized that students who are blind and visually impaired needed instruction in a disability-specific curriculum to have a comparable postschool QOL as their sighted peers (Monson, 2009). The ECC was designed to meet the unique educational needs of students who were blind and visually impaired and intended to improve the academic and post-school outcomes for students with VI (Farrell, 2009). The ECC covers nine topics: compensatory and functional skills, orientation and mobility, social skills, independent living skills, leisure and recreation skills, career and vocational skills, technology,

sensory efficiency, and self-determination. According to Monson (2009), there is little research investigating the extent to which instruction in EEC leads to an improved postschool QOL. Monson examined the relationship between instruction in the ECC for students who are VI and postschool QOL outcomes and identified that the ECC areas of Independent Living Skills and Self-Determination as essential areas of instruction, and significant, relatively strong predictors of post-school outcomes.

Table 2.2 *National Agenda Goals*

Priority Goals	What do the goals address?
Goal one	Students and their families will be referred to an appropriate education program within 30 days of identification a suspected visual impairment.
Goal two	Policies and procedures will be implemented to ensure the right of all parents to full participation and equal partnership in the education process.
Goal three	Universities with a minimum of one full-time faculty member in the area of VI will prepare a sufficient number of educators of students with VI to meet the personnel needs throughout the country.
Goal four	Service providers will determine the caseloads based on the needs of students and will require ongoing professional development for all teachers and orientation mobility instructors
Goal five	Local education programs will ensure that all students have access to a full array of placement options
Goal six	Assessment of students will be conducted, in collaboration with parents, by personnel who have expertise in the education of students with VI.
Goal seven	Instructional materials need to be available to students in the appropriate media and at the same time as their sighted peers.
Goal eight	Educational and developmental goals, including instruction, will reflect the assessed needs of each student in all areas of academic and disability-specific core curricula.

In 1990, EAHCA was amended and renamed the IDEA. IDEA requires that educators must: “ensure that all children with disabilities have available to them free and appropriate public education that emphasizes special and related services designed to meet their unique needs and prepare them for further education, employment, and independent living” (IDEA, 20 U.S.C. § 1401 [d][1][A]). In the EAHCA, and now the IDEA, the continuum of alternative placements, from the least restrictive to the most restrictive environment were based on the individual needs of each student (McMahon & Sacks, 2014). In the last few years, students who are blind or VI have been educated using the entire continuum: in general education classrooms, resource rooms, specialized or residential schools, or homeschooled.

Residential and specialized schools continue to play a role in the education of students, adolescents, and youth who are blind or VI. Ajowan et al. (2015) asserted that inclusion is viewed as a commitment to educating each child, using available services and supports, to the maximum extent possible in the classroom he or she would otherwise attend. Inclusion supporters suggested that children who are blind or VI should be allowed to interact with peers because the resulting proximity and modeling would lead to language and social skills acquisition which may not be possible in a segregated setting. Benefits of inclusion also included increased academic motivation and self-esteem and promotion of a sense of belonging. Critics of inclusion argue that (a) inclusion can result in social isolation, (b) there are limited opportunities for students to become competent in the specialized competencies such as ECC, and (c) the majority of children who are in public schools do not become socially integrated because teachers of children with VI are frequently saddled with broad and diverse caseloads and rely heavily

on a service delivery model that favors itinerant and teaching consultant approaches (Ajowan et al., 2015). McMahon (2014) indicated that it is imperative to ensure the continuum of the education that each state offers to every child who is blind or VI. Also, the goal of the field of VI is to prepare students who are blind or VI, including students with additional disabilities, to lead quality lives and reach their highest potential academically as well as functionally.

2.3 Educational Measurements

Since the enactment of the EAHC the educational achievements of children who are blind or VI in SC are measured through their IPEs, and reported through the District School Report Cards / Accountability Reports (www.ed.sc.gov). According to these reports, the success of the education of children who are blind or VI, typically are measured through academic achievement, test scores, graduation rates, overall students' performance, and placement after graduation. However, Schalock and his colleagues asserted that such quantitative measures are insufficient for measuring the success of high school graduates who are VI or blind (Schalock & Verdugo, 2002; Schalock, 2007). Schalock suggested that qualitative measurements of success through the QOL concept adds a direction, meaning, and social validity, as well as outcomes.

In the 1980s, the concept of the QOL was embraced as a new and changing vision for individuals with disabilities (Schalock, 2011; Schalock & Verdugo, 2002). Since then, the QOL focus and application has expanded to include research in the fields of education, special education, healthcare (physical and behavioral), social services (disabilities and aging), and families (Schalock, 2004). Verdugo et al. (2005) supported this growing interest in determining the extent to which programs and service treatments

improve the quality of life for individuals with disabilities. Many positive changes have occurred in the areas of special education as the concept of the QOL was embraced as (a) a clear shift in educational policy from an emphasis on the process of education concerns about the desired outcomes of schooling and standards against which schools and education-related outcomes can be judged, (b) the movement to include students with disabilities as full-time members of regular education (Schalock, 2011; Schalock & Verdugo, 2002). According to Brown and Brown (2005), the QOL approach, as presented in Schalock and Verdugo's works (2002) recognizes the holistic nature of QOL and provides a rationale for application. In this study, I evaluated the personal outcomes of the lived experiences of six adults who are blind, as defined in the eight-core domains and indicators of Schalock's conceptual and measurement model. The following review of the literature supports the theoretical and conceptual framework for this study.

2.4 QOL Framework

There are numerous definitions of QOL (Rodriguez et al., 2009; Schalock, 1994; Schalock & Verdugo, 2002). There is no unanimously accepted definition of QOL due to the dynamic nature and diversity of this concept (Schalock & Verdugo, 2002). QOL has been defined as individuals' perceptions of their positions in life in the context of the culture and value systems, goals, expectations, standards, and concerns in which they live (World Health Organization Group [WHO], 1995). Felce and Perry (1995) defined QOL as general well-being influenced by objective circumstances and subjective perceptions across a variety of QOL domain issues. Schalock (Schalock & Verdugo, 2002; Schalock, 2004) further defined the QOL definition of [individuals'] quality of life as a multi-

dimensional phenomenon composed of eight core domains, which are influenced by personal characteristics and environmental factors.

These eight core domains are Personal Development, Interpersonal Relations, Social Inclusion, Rights, Emotional Well-Being, Physical Well-Being, and Material Well-Being, and apply for all people, although they may vary individually in relative value and importance. The Special Interest Research Group on QOL (2000) noted that QOL is essential and should be thought of in the same way for all people with and without a disability. Various researchers have introduced QOL models for use with the general population and special education (Hatton 1998, Schalock & Verdugo 2002, Schalock, 2011).

The concept of QOL in special education first appeared in Schalock's writings in the mid-1980s in the area of intellectual disabilities and was based on the evaluation of community-based residential and vocational programs in Nebraska. In 2001, Schalock stated that although they had succeeded in placing people into more independent and productive environments, they had overlooked an important item, their quality of life. Hatton (1998) supported Schalock's findings and noted that these models, as used with people with intellectual disabilities, emphasized the multidimensional nature of QOL. Today Schalock's model of QOL for people with disabilities is the most widely accepted (Rodriguez et al., 2009; Guerrette & Smedema, 2011). As applied to special education, this multidimensional model includes the most commonly used indicators per core QOL domain. These core domains are essential to the hopes and dreams of all persons and resonate with the desire that each person can live more independently (Schalock, 2011). Schalock's conceptual and measurement model has three empirically derived and

validated factors (a) **Independence**, (b) **Social Participation**, and (c) **Well-Being**. Each factor consists of domains, and each domain contains of indicators. Schalock and Verdugo (2002) defined “core domains” as a set of factors composing a person’s well-being. Each of the domains consists of indicators that are identified as specific perceptions, behaviors, or conditions that reflect a person’s well-being (See Table 2.3).

Table 2.3 *QOL Factors, Domains, and Indicators*

Factors	QOL Domains	Indicators
Independence	Personal Development	Education, personal competence, and performance.
	Self – Determination	Autonomy, personal control, goals and personal values, and choices.
Social Participation	Interpersonal Relations	Interactions, relationships, and support.
	Social Inclusion	Community integration and participation, community roles and social supports.
	Rights	Human rights, respect, dignity, equality, legal, citizenship, access, and due process.
Well - Being	Emotional Well - Being	Contentment, self-concept, and freedom from stress.
	Physical Well-Being	Health status, activities of daily living, and leisure.
	Material Well-Being	Financial status, employment, and housing.

The QOL journey has been both challenging and productive (Schalock & Verdugo, 2002; Schalock, 2004). The challenges have involved overcoming the belief that an enhanced QOL is a realistic and obtainable goal for all people, including those with disabilities. According to Schalock (2004), overcoming these challenges has entailed productive in-service delivery, research and evaluation techniques, and identification of personal outcomes reflecting a life of quality.

The quality revolution of the 1980s and the reform movement of the 1990s initiated significant changes for how people view the purposes, characteristics, responsibilities, and desired outcomes from health and human service programs. Schalock and Boham (2003) suggested focusing on outcomes guided by goals that are related to person-referenced and valued outcomes and then redefining clients as customers. In the past two decades, there has been a growing interest in evaluating to what extent programs and service delivery improves the quality of life for individuals with disabilities, including those with VI (Verdugo et al., 2005).

QOL is a difficult concept to define and even more difficult one to measure (Eiser et al., 2000). Measuring QOL involves identifying what specific things have come to be valued by individuals and matching this to individual perceptions of personal satisfaction or happiness (International Association for the Scientific Study of Intellectual Disabilities [IASSID], 2000). Eiser et al. (2000) asserted that an individual's perception of their QOL is unique, and efforts must be made to elicit information from the individual. This consideration of measuring from the individual's perspective is both subjective and objective. Hatton (1998), argued that summarizing objective and subjective assessments of several QOL dimensions to produce a single score is a process fraught with difficulty. But Hatton (1998) supported the idea that for services to be evaluated using a QOL framework, both objective and subjective aspects across a range of dimensions need to be considered. Hatton tried to stimulate a debate about QOL as a concept and a method of practice. He suggested that researchers interested in the QOL approach or other forms of knowledge-gathering need to engage each other in debate, including people with mental

retardation who are the “objects,” “subjects,” or “participants” in such knowledge gathering.

Schalock and Boham (2003) suggested focusing on measuring outcomes that are specific to person-referenced goals and re-defining clients as “customers.” Importantly, Guerrette and Smedema (2011) noted that people with low-incidence disabilities, measured objectively, have a lower quality of life than in the general population. They also found that when measured subjectively, a lower level of QOL was not evident in people with disabilities compared to those without disabilities. In their guidelines for measuring QOL, Guerrette and Smedema concluded that domain scores and descriptions are more useful and expressive than the total scores or descriptions that are aggregated from separate domain data. Additionally, subjective measurements appear to level the playing field for individuals with disabilities. However, some reliability problems are associated with using subjective assessments, such as inconsistency, inaccuracy, and response biases. To address these issues, Astegger (2006) recommends using multiple methods and perspectives.

QOL, in general, is a subjective query, important for person-centered services. Subjective measures reflect satisfaction with the life domains weighted following the value of the individual (Astegger, 2006). In the 1980s, QOL was introduced in the fields of education, health care, and social services (Schalock & Verdugo, 2002). According to Schalock (2004), the purpose of the QOL assessment is not to compare people. The purpose is to gather individual scores and profiles that can be used to communicate results through basic questioning of the people in the inquiry. These results should allow all service providers to consider how to enhance their clients’ quality of life. In the past

two decades, there has been a growing interest in evaluating to what extent programs and service delivery improves and impacts the QOL for individuals with disabilities, including those with visual impairment (Verdugo et al., 2005). The research into QOL has grown significantly from both a qualitative and quantitative view (Schalock & Verdugo, 2002). Next, I present a review of literature that addresses QOL factors, its domains and indicators.

2.5 Qualitative and Quantitative Studies

The concept of QOL has increasingly become the focus for research and application in the fields of education, special education, health care (physical and behavioral), social services (disabilities and aging), and families (Schalock, 2004). According to Schalock and Verdugo (2002), scientists, practitioners, service providers, administrators, and others involved in human services have paid particular attention to the development and application of the concept to improve services. Also, there is growing interest in the extent to which programs and service treatments can improve the QOL for individuals with disabilities (Verdugo et al., 2005).

The National Longitudinal Transition Study-2 (NLTS2), founded by the National Center for Special Education Research at the Institute of Education Services, United States Department of Education, was designed to collect data from youth with disabilities (Newman et al., 2011). The purpose of NLTS 2 was to collect data from a sample of 12,000 participants from multiple sources in five waves beginning in 2001 and ending in 2009. The NLTS2 was a ten-year study of the characteristics, experiences, and outcomes of a representative sample of youth with disabilities who were thirteen to sixteen years old in grade seven or above, beginning on December 1, 2000, in the United States. The

NLTS2 provided a unique source of information to help in developing and understanding the experiences of secondary school students with disabilities nationally as they go through their early adult years (Newman et al., 2011). NTLS2 data for the study were obtained from scripted telephone interviews with youth with disabilities. The study included a representative sample of secondary school students with disabilities who were 13 to 16 years old and receiving special education services under the IDEA in the 2000–01 school year. The executive summary presented the findings related to these critical domains (a) postsecondary education enrollment, educational experiences, and completion (b) employment status and characteristics of young adults' current or most recent job (c) productive engagement in school, work, or preparation for work (d) residential independence, the prevalence of marriage, parenting, and aspects of their financial independence, and (e) social and community involvement, including friendship activities and community participation in both positive and negative ways.

The transition from high school to post-school life is difficult for any student, let alone a student with a disability (NCRS, 2013). The NTLS2 findings show that students with disabilities are less likely to attend post-secondary education, be employed, and live independently compared to their peers without disability (Newman et al., 2011). Also, the NTLS2 study compared data between disability categories. The study indicated that young adults with visual and hearing impairment were more like to attend postsecondary school (71% and 75%) than those with emotional disturbance, multiple disabilities, or mental retardation (53%, 33%, and 29% respectively). Also, young adults with visual and hearing impairment were more likely to have enrolled in a 4-year college or university (40% and 34%) than those with emotional disturbances, autism, other health

impairments, multiple disabilities, or mental retardation (7% to 20%). Also, youth with visual impairments were more likely to have attended a four-year college than those with learning disabilities, orthopedic impairments, or traumatic brain injuries (21%, 26%, and 19%, respectively). Young adults with visual or hearing impairments were more likely to have received accommodation and support from their schools because of their disability (59% and 53% respectively) than were young adults with speech/language impairments, other health impairments, learning disabilities, emotional disturbances, or mental retardation (12% to 24%).

Young adults with VI were less likely to be employed than young adults with other health impairments, speech /language impairments, or learning disabilities (44% to 67%). An interesting finding of the study was that young adults with VI were more likely to have disclosed a disability to their employers (75%) compared with young adults with learning disabilities, speech/language impairments, other health impairments, emotional disturbances, or traumatic brain injuries (19% to 30%). In addition, young adults with VI were more likely to have taken lessons or classes outside of formal school enrollment (38%) than were young adults with learning disabilities, mental retardation, other health impairments, or traumatic brain injuries (12% to 20%). They also had a significantly higher rate of participation in volunteer and community service activities (44%) than did young adults with speech/language impairment or mental retardation (26% and 19%). Young adults with VI were also more likely to belong to an organized community or extracurricular group than young adults with emotional disturbances (51% versus 32%).

Joseph (2010) conducted a study to explore the educational, vocational, and social experiences of sixteen college students who were VI to determine how these experiences

impacted them educationally and socially (see elaboration on this study in chapter three). The purpose of the study was to understand the experiences of college students and college-graduate students who were VI. Joseph reported that there are ten life domains associated with QOL that can be affected by disability related disruption. These domains impacted: physical health, mental health, work leisure activities, financial situation, relationship with spouse, family relations, other social relations and spiritual expressions. Blindness can disrupt one's life and may be conceptualized in regard to its' effect on the person's well-being or quality of life.

Russello and D'Allura (2000) followed twenty-five individuals with VI who received Career Incentive Awards between the years 1986-1995. Each year, this program (sponsored by a Vision Rehabilitation Agency in the New York metropolitan area) honored five students with visual impairments each year who lived and attended residential schools in the US northeast. Students submitted a written application, and awards were given based on merit, not financial need. Data included two sources of information (a) applications submitted by the students when they applied for the award and (b) telephone interviews with the individuals who received the awards. The interviews gathered information related to the individuals' education, career, and employment status. Additional information included the usefulness of the award and monetary value in assisting individuals to achieve their educational and career goals.

Demographic characteristics of the participants included twenty-five participants (14 men and 11 women), ranging in age from 19 to 60 years with visual status of twenty legally blind (20/200 visual acuity) and five blind (no light perception). Concerning education, the study indicated that this was a very highly educated group. Six individuals

had bachelor's degrees; twelve had a master's, doctoral, or law degree; and seven were working toward their undergraduate degree at the time of the study. Thirteen of the twenty-five participants were employed at the time of the interview, eight in the full-time positions, and five in part-time positions. Of twenty-five participants, twenty-two considered themselves successful. They defined success as achieving personal goals and being happy in life. Receiving the award gave them pride, appreciation, and motivation for future endeavors (Rusello & D'allura, 2000). Participants noted that making or having a great deal of money does not necessarily make a person successful. They also reported that the use of adaptive devices or assistive technology as part of their success. The adaptive devices played a role in their success in education and employment by allowing them to succeed.

McAbee (2005) conducted an interesting study of QOL of deaf adults. McAbee (2005), found that current research in QOL within the deaf and hard of hearing population is mostly quantitative. She researched how deaf adults defined their QOL using qualitative methodology and found that the deaf community is small and robust, like a "family." *Being deaf* is an identity, which includes culture, language, history, and values. McAbee also found that deaf adults consider their support network, such as friends and family to be important to a good QOL. Moreover, McAbee found that deaf adults value independence. In exploring the issues of services, McAbee found that services provided by state agencies (such as the vocational service department) and interpreting services (especially in the medical field) did not always increase one's QOL.

Rosenblum et al. (2020) investigated the impact of COVID-19 on 1,921 adults who are blind or have low vision in the United States (all 50 states, the District of

Columbia, and Puerto Rico were represented). The COVID-19 pandemic began to affect Americans in late February 2020. According to Rosenblum et al. (2020) data for the Flatten Inaccessibility survey were collected through an accessible online survey on healthcare, transportation, employment, education, social experiences, access to food, meals, supplies, and voting. Demographic characteristics of the participants (a) Level of vision, 65% of the participants were blind and 35% had low vision, (b) Gender, Female, 63.4%; Male 35.2%; transgender or gender nonconforming , 1%; no response, 0.37%, (c) Race or ethnic background, White, 77%; Hispanic, Latinx or Spanish origin, 7%; Black or African American, 7%; Multiracial, 4%; Asian, 3%; American Indian or Alaska Native, 1%; Native Hawaiian or Pacific Islander, 0.11%; and Other, 1%, and (d) Age, 18-34 years, 23.5%; 35-54 years, 34%; and 55 and older, 42.5%. Additionally, 43% of participants reported having an additional disability, with diabetes, hearing impairment, and significant psychiatric disorders being most frequently reported.

Some key areas of concerns identified in the study are (a) Transportation, 68% of the participants had concerns about transportation, related to safety and access to transportation and fears that they will not be able to get themselves or loved ones to COVID-19 test sites or healthcare providers if they were to get sick, (b) Healthcare, 54% of the participants had concerns about healthcare, and 59% felt their underlying health conditions made them vulnerable to COVID-19 complications. Also, 30% of participants reported using telehealth, but 21% of these participants reported the telehealth platform was not accessible, (c) Employment, 47% of the participants had concerns about the employment, with 38% reporting accessibility problems with technology tools need to do their job, and 22% reporting that they were unable to access technology at home, (d)

Education, 47% of the participants had concerns about their children's education, with 60% reporting the technology tools that they need to use were not accessible, and 90% reported they received no training in the new technology, (e) Voting, although 91% of the participants were registered to vote, 39% were unsure if they had an accessible voting system, and 23% reported they did not have an accessible system. The data gathered from the participants not only highlighted challenges related to COVID19, but also provided documentation of the systemic issues that individuals who are VI encounter on daily basis (Rosenblum et al., 2020).

In conclusion, the current approach to QOL research in the area of the disabilities can be characterized by (a) its multidimensional nature involving core domains and indicators, (b) use of the objective and subjective measures, (c) use of multivariate research designs, (d) multiple environments, and (e) increasing involvement of "clients," "persons," or "individuals" in design and implementation of QOL assessment, research, and evaluations (Verdugo et al., 2005, Schalock & Verdugo, 2002). Next, I present a review of literature in the field of blindness and VI according to each QOL domains.

2.6 Personal Development Domain

Schalock and Verdugo (2002) noted that Personal Development domain is the narrowest research domain in the literature review. There are few research studies done with individuals with VI. Research supported that braille literacy and technology can advance students with VI education. Teachers and professionals in the field of VI have long recognized the reliance of braille for any students whose vision is not good enough to read regular print comfortably and at a competitive rate for a sustained time (Silverman & Bell, 2018). Table 2.4 summarizes some of the studies and their findings.

Table 2.4 *Personal Development Domain*

Definition/ Indicators	Author(s)	Year	Participants	Instrument(s) used	Findings
<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Education Personal Competence Performance</p>	Rosner & Perlman	2018	96 adults with VI	<p>Face to face Interviews</p> <p>Observation</p> <p>Vision Related QOL Questionnaire</p> <p>Observations of computer usage</p>	<p>The participants were highly satisfied with the computer-based assistive devices, including voice software, braille display, screen readers, video magnifiers or, software with magnifiers.</p> <p>The study found that participants used their computers for reading and writing e-mails, surfing the Internet, at least once a week. Other activities included writing documents, listening to music, and reading news. Participants were less likely to engage in activities such as surfing on forums, playing games, and browsing entertainment and service web sites (bank or health care).</p> <p>Participants reported that communication with people through computers had improved to a large extent. Computers are used mostly for leisure averaging three hours per day.</p> <p>The study examined links between braille literacy and life outcomes. Participants were classified as Primary readers, secondary readers, and non-readers. Primary and secondary braille readers were equally likely to have some form of paid employment. Also, primary braille readers were marginally less likely to be in the unemployment category.</p>

Schalock & Verdugo (2002)	Silverman & Bell	2014	419 participants with VI ages 18 -64	Satisfaction with Life Scale (SWLS)	Primary braille readers reported being more satisfied with their lives and having higher self-esteem than two other groups. Braille literacy is critical to their self-esteem and acceptance of Blindness.
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2.7 Self-Determination Domain

The Self-Determination domain for people with disabilities has its roots in the normalization, independent living, and disability rights movement of the 1960s and 1970s and the self-advocacy/self-help movement of the 1980s and refers to their rights to control their lives (Wehmeyer & Schwartz, 1998). According to Schalock and Verdugo (2002), Self-Determination domain is the smallest research domain in the literature review. From an individual perspective, the components of the the domain are “based on the assumption that people want to control their own lives and that self-determination is what life is all about” (Schalock & Vedugo, 2002, p. 302).

Guererro (2017) defined self-empowerment as the act of taking control of life, setting goals and making positive choices. Participants in their study experienced a sense of self-empowerment because they could read, write and communicate with others through the use of braille. Their self-empowerment intertwined with self-advocacy and allowed them to be enthusiastic and decisive about their future. Parental and TVIs support contributed to their self-empowerment. Parental commitment consisted of investment of time, finances, and support. TVIs commitment was in terms of service delivery, resources, and efforts to prepare the students for the future.

Griffin-Shirley and Nes (2005) compared students who were VI (residential schools) with their sighted peers and found no significant difference between sighted children and those with VI regarding their levels of self-esteem, empathy towards others, and bonding with pets. The majority of the participants who were VI (97%) were pet owners. Table 2.5 summarizes some of the studies done with individuals who are VI and their findings.

Table 2.5 *Self-Determination Domain*

Definition/ Indicators	Author(s)	Year	Participants	Instrument(s) used	Findings
<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators:</p> <p>Autonomy Personal Control Goals Personal Values Choices</p> <p>Schalock & Verdugo (2002)</p>	Guerrero	2017	4 students with VI ages 16-17 years.	Semi-Structured Interviews	<p>Participants demonstrated tenacity when they overcome initial difficulties in learning braille and expressed gratitude for their parents, and TVIs. Goal-setting: Students set goals for themselves involving furthering their education by learning technology, advanced math skills, learning braille music, and learning to play instruments. Goals were self-taught, or they advocated for themselves to be taught by TVIs. Participants had defined plans for their future, and they communicated no wavering or indecisiveness when it came to their future goals.</p> <p>Self- empowerment intertwined with self- advocacy. Students experienced a sense of self-empowerment because they can read, write, and communicate with others through the use of the braille. This self-empowerment has allowed these students to be enthusiastic and decisive about their future. Commitment on the part of the students, parents, and TVIs. Students exhibited a significant commitment to their learning, as evidenced by braille and academic success. Parental commitment consisted of investment of time, finances, and support. TVIs commitment was in terms of service delivery, resources, and efforts to prepare the students for the future.</p>

<p>Indicators: Contentment Self – concept Freedom from stress</p> <p>Schalock & Verdugo (2002)</p>	<p>Griffin – Shirley & Nes</p>	<p>2005</p>	<p>71 students with VI from residential schools</p> <p>88 sighted peers</p>	<p>Demographic Questionnaire Bryant Index of Empathy for Children and Adolescents (IECA) Companion Animal Bonding Scale (CABS)</p>	<p>Most of the participants lived in households with two adults and 4-6 siblings. The vast majority (97%) were pet owners.</p> <p>The study found no significant difference between sighted children and those with visual impairment regarding their levels of self-esteem, empathy toward others, and bonding with pets.</p>
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2.8 Interpersonal Relations Domain

According to Schaolock and Verdugo (2020) the Interpersonal Relations domain has attracted the attention of the reserchers in the field of educational rserach and journals. Most of the research and studies on the Interpersonal Relations domain are related to adults who are blind or VI. Individuals who are VI or blind require various degrees of support and assistance in their daily living activities.

Silvia-Smith et al. (2007) defined the primary support person as a family member or friend who assisted a person who is blind or VI with all day-to-day activities.

Cimarolli and Boerner (2007) reported that some of the most supported activities for individuals who are VI were (a) transportation to medical appoitments, (b) shopping and putting groceries away, (3) administrative tasks such as check writing, balance check book, letter writing, mail sorting, and filling.

Guerette and Smedema (2011) explored the relationship between perceived social support and well-being in adults with VI by measuring social support, depression, satisfaction with life, and a sense of well-being. They found that individuals with VI who have higher levels of employment and social support reported higher levels of physical, economics, and social well-being. Furthermore, higher levels of social support were associated with higher levels of satisfaction with life. The depressive symptoms were associated with age and level of support. The study found that the older participants were able to cope better with deppressive tendencies, and low levels of support were associated with a higher level of depressive symptoms. Table 2.6 summarizes some of the research done with individuals who are blind or VI related to Interpersonal Relations domain and their findings.

Table 2.6 *Interpersonal Relations Domain*

Definition/ Indicators	Author(s)	Year	Participants	Instrument(s) used	Findings
<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Interactions Relationships Support Systems</p> <p>Schalock & Verdugo (2002)</p>	Jessup et al.	2018	12 adolescents with VI mainstreamed into public school	Questionnaire Lubben Social Network Scale (LSNS -6)	Data revealed that these students have very few opportunities to show competence and less autonomy and choices in the classrooms than do their sighted peers. Activities outside the classroom were rated higher on choice opportunities, identity development, and resilience.
	Guerette & Smedema	2011	199 individuals with VI	Center for Epidemiologic Studies Depression Scale (CES -D-10) Satisfaction with Life Scale (SWLS) Sense of Well - Being Inventory (SWBI) Survey Telephone interviews CES-D-10	<p>Age and level of support were associated with depressive symptoms.</p> <p>Older participants were able to cope better with depressive tendencies, and low levels of social support were associated with a higher level of depressive symptoms.</p> <p>Higher levels of social support were associated with higher levels of satisfaction with life.</p> <p>Individuals with VI who have higher levels of employment and social support reported higher levels of physical, economic, and social well -being.</p>

<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Interactions Relationships Support Systems</p> <p>Schalock & Verdugo (2002) Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL</p>	Lifshitz et al.	2007	2,000 students with VI attending public or residential schools	Satisfaction with Life Scale (SWLS)	The study found no differences in self-concept between the two groups of students, sighted or visually impaired.
	Cimarolli & Boerner	2007	20 adults primary support for VI individuals ages 36 to 88	Face to face Interviews Social Network Map Social Network Grid	Some of the most supported activities that individuals with VI were: First, transportation to medical appointments or for leisure activities was identified as one of the most common support activities. Second, shopping and putting groceries away. Third, administrative tasks, such as check writing, balance checkbook, letter writing, mail sorting, and filing. The most frequent social and emotional support was received from family members, followed by instrumental and received emotional support from friends.
	Caballo & Verdugo	2005	6 students with VI ages 4 to 18 years 64 sighted peers ages 4 to 18	Observational checklist One- to -one Small group Large group	VI affects blind children's social relationships. The lack of the ability to read body language and emotional cues of others hinders the development of social skills and contributes to fewer and more superficial interpersonal relationships. The study found that when mothers and teachers are taught to empower adolescents with visual impairments, the students have high and positive social-emotional adjustment to self-concept and adjustment to the disability.

<p>Indicators: Interactions Relationships Support Systems</p> <p>Schalock & Verdugo (2002)</p>	Kef et al.	1997	316 VI and blind youth adolescents ages 14 -23	<p>Surveys Face to face Interviews</p> <p>However, when discussing friendships and spending social time together, sighted peers score significantly higher than visually impaired adolescents. This disparity in the amount and quality of leisure time, as well as acquiring confrontational and betrayal skills is due to the inability to use visual communication cues, such as facial expressions and body language. The quality of friendships was higher for sighted peers than for visually impaired adolescents. Parents are a crucial source of emotional and social support.</p> <p>The size and range of personal networks of adolescents with VI were smaller than those of sighted peers. The size of the group of friends was affected by gender and degree of VI. Concerning the composition of the network, the most significant sectors were friends, family, members, especially parents, and extended family members.</p>
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2.9 Social Inclusion Domain

Several federal laws such as the EAHCA, later amended and renamed the IDEA, Section 504, the Rehabilitation Act of 1973 (P.L. 93-112), and the American with Disabilities Act (P.L. 101 - 336) have laid the groundwork for integrating the individuals with disabilities into schools and communities. This is referred to as the Social Inclusion domain. Also, the Freedom Initiative of 2001 was designed to improve access to community life for individuals with disabilities through enhanced use of technology, high-quality education, and rigorous enforcement of existing laws (Carlson, Bitterman, Daley, 2010). According to Carlson et al. (2010), community integration or community access can mean different things at different ages. For adults, it may include transportation, employment, and children's access to higher education and appropriate social support.

Research has identified many social support systems for individuals who are blind (Kef 1997, Cimarolli & Boerner, 2005; Papakonstantinov & Papodopolous, 2010). Such social support systems can be perceived either as positive, negative, practical, formal (school personnel and professionals), or informal (family and friends). Additionally, research indicates that students who are blind and VI have difficulty making friends due to the inability to see facial cues and body language and the lack of awareness of socially unacceptable behaviors such as rocking, eye-poking, or other blindisms. This inability to receive visual cues from the environment restricts children's social development and ability to make friends (Yildiz & Duy, 2013). Therefore, children who are blind are more socially isolated, with fewer opportunities for support from peers. Table 2.7 summarizes some of the studies done with individuals who are blind or VI and their findings.

Table 2.7 *Social Inclusion Domain*

Definition/ Indicators	Author(s)	Year	Participants	Instrument(s) used	Findings
Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.	Kef	1997	316 youth & adolescents with VI and blind ages 14-23	Surveys Face to face Interviews	Kef found a significant relationship between gender and age: females had more friends than males. Parents and family are essential sources for emotional and practical support for their children who are VI or Blind, the presence of VI is a significant predictor of the difficulties that children with VI have with social relations.
Indicators: Community Integration and participation Community Roles Social Support	Caballo & Verdugo	2005	64 students with VI ages 4 to 18 years 64 sighted peers ages 4-18	Observational checklist One-to-one Small group large group	The study found that micro (specific skills and body language) and macro components of social skills (play, cooperation, expression, and recognition) contribute to the QOL of social integration among children with VI. They have difficulties participating in activities and games with sighted peers.
	Cimarolli & Boerner	2005	86 adults with VI ages 22-64 years	Interviews Social Network Map Grid	VI plays a vital role in the acquisition and refinement of skills that are relevant for participating in conversations. Higher levels of social support were associated with higher levels of satisfaction with life.
Schalock & Verdugo (2002)	Carlson et al.	2010	3,1004 children with disabilities ages 3 -5 years.	Telephone interviews PEELS Questionnaire	PEELS was designed to describe young children with disabilities, their experiences, the services they receive, and their performance. Family members are the primary source of positive support for adults who are VI or Blind.

<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Community Integration and participation Community Roles Social Support</p> <p>Schalock & Verdugo (2002)</p>	Renaud et al.	2010	64 participants ages 65 and older	Health-Related QOL Questionnaire	<p>Low levels of social support were associated with high levels of depressive symptoms.</p> <p>Children's participation in at least one extracurricular activity varied significantly by how well the family transportation met children's needs participation in several activities varied by household income.</p> <p>The study found that Health-Related QOL (HRQOL) was related more significant level of participation on social roles, higher perceived activity level, use of writing aid, and greater satisfaction with participation in social roles. The severity of VI was correlated with HRQOL.</p> <p>For older adults with VI, the level of participation in social roles was the best correlate to explain HRQOL.</p>
	Holbrook et al.	2009	25 individuals with VI ages 23 - 42	Interview QOL Index Visual Function Questionnaire	<p>Higher levels of perceived social support were associated with positive indicators of well – being.</p> <p>Measurement of QOL can help determine factors that have the most positive influence on the lives of people with VI and maybe addresses in the educational and rehabilitation interventions.</p>
				Lubben Social Network Scale (LSNS) CES -D SWLS	<p>Age and employment were both positively significantly associated with life satisfaction.</p> <p>The degree of the severity and the age of onset not of VI may not affect the well – being of persons with VI.</p>

<p>Indicators: Community Integration and participation</p> <p>Community Roles Social Support</p>	Guerette & Smedema	2011	199 individuals with VI Age means 46.1 years.	Telephone Interviews	<p>Age and level of social support were found to be significantly associated with depressive symptoms in the participants.</p> <p>Age and employment were positively associated with life satisfaction.</p> <p>Higher levels of social support were associated with higher levels of satisfaction with life.</p>
	Hong & Erin	2017	<p>23 students in the VI program</p> <p>17 mentors with VI</p>	Interviews Questionnaire	<p>The project helped students in the program to understand the day-to-day experiences of working adults with VI.</p> <p>Students in the VI program did not have enough experiencing visual impairment as a “normal” experience.</p> <p>Mentors did not have the opportunity to observe skills related to teaching.</p> <p>Communication skills: asking if assistance was needed rather than assuming that the mentor wanted guidance.</p>
	Mellavane & Reinhard	2017	241 elderly adults with VI	Questionnaire	<p>The quality of social networks was significant for improved functioning and well-being.</p> <p>There is a positive association between social support and life satisfaction.</p> <p>Negative support comes in the lack of understanding of the competence of blind individuals to accomplish tasks without the aid of visual input, overprotectiveness, additional help, excessive praise, and limited opportunities for healthy development.</p>

	Rosenblum et al.	2020	1,921 participants who are blind or have low vision	Flatten Inaccessibility Survey	43.5% of the participants live with a spouse or a partner, 33.6% lived alone, and 15.3% lived with other family member
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2.10 Rights Domain

The Rights domain is the smallest research domain in the literature review (Schalock & Verdugo, 2002). The Rosenblum et al. (2020) study indicated a high rate of voter registration. 91% of the 1,790 of the participants reported that they were registered to vote. Another interesting fact of the study was how the participants typically vote: (a) 41% went to a polling location and voted with an accessible ballot-making system, (b) 28% voted by mail, and (c) 18% went to a polling location and voted with assistance from a family member, friend, or other individual. Rosenblum et al. (2020) questioned the participants about the voting and accessibility. It was concerning to the researchers in the study that just over 25% of the participants knew whether they had an accessible system for voting. Approximately 1 of 10 participants who responded to the polling question reported that they have voted without assistance. There were adults who are blind or VI who could benefit from an accessible voting system but are unsure if one is available. Another concern was that at a physical polling location, there is no guarantee of accessibility. Participants reported having difficulty accessing the ballot and the volunteers have trouble getting voting interface to work, and it takes time for them to figure it out. Also, mail-in ballots can present a challenge of the individuals who are blind or VI. If they are not accessible, they will require sighted assistance to vote, which precludes one's ability to vote independently and privately (Rosenblum et al., 2020).

2.11 Emotional Well - Being Domain

There are very few research studies in the Emotional Well-Being domain with individuals who are blind or VI. Table 2.8 summarizes some of the studies done with individuals with VI and their findings.

Table 2.8 *Emotional Well-Being Domain*

Definition/ Indicators	Author(s)	Year	Participants	Instrument(s) used	Findings
<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Contentment Self – concept Freedom from stress.</p> <p>Schalock & Verdugo (2002)</p>	Lifshitz et al.	2007	<p>40 adolescents with VI</p> <p>20 attending a public school</p> <p>20 attending a residential school</p> <p>41 sighted adolescents</p>	<p>Self – Concept Questionnaire</p> <p>Quality of Friendship Scale</p> <p>Nottingham Adjustment Scale</p> <p>Teacher's Evaluation of Social and Emotional Adjustment Scale</p>	<p>The study focused on the personal and social adjustment of adolescents with VI who are at the stage of formulating their personal and social identity while coping with issues of VI.</p> <p>Sighted group and VI group rated esteem by their mothers and teachers higher than the esteem by their friends or fathers.</p> <p>There were no differences in self – concept between sighted adolescents and those with VI.</p> <p>Regarding attitudes towards blindness, the participants agreed that losing vision is one of the worst things that can happen.</p> <p>The study explained the high scores on attribution styles with the resilience (a pattern of positive adaptation in the face of significant risk or adversity) effect.</p> <p>Children with disabilities succeed in adapting to life despite the risk of adversity.</p> <p>There is a low quality of friendships and social interactions with adolescents with VI. The inability to use nonverbal communication makes it difficult for them to acquire social skills.</p> <p>Adolescents with VI showed a lower level of confrontation and betrayal that may reflect their fear of losing their friends and coping with their impairment.</p>

2.12 Physical Well-Being Domain

The QOL research literature in the Physical Well-Being domain includes both qualitative and quantitative studies. Holbrook et al. (2009) noted that past research has quantified the physical activity levels of persons with VI and has been limited to children and adults. Children and youth with VI and their parents have identified barriers to physical activity as (a) lack of opportunity to participate, (b) lack of friends or family with whom to participate, and (c) being the brunt of teasing. Parents suggested the following recommendations to improve the participation of their children with VI in physical activities (a) increasing community support, (b) increasing public transportation, and (c) hiring teachers who are trained to use more adaptive physical education classes (Ward et al., 2011; Wiskochil et al., 2009; Stuart et al., 2006).

Furthermore, Haegle et al. (2017) reported that by allowing students to provide information from their own perspectives, we gain a better understanding of how to identify strategies to improve instruction on physical education. A review of the literature supported the importance of physical education classes, adaptive physical education, and levels of physical activity. The trend toward inactivity in students who are blind or VI is consistent with the adult population who are blind and often leads to a lower quality of life. However, Wiskochil et al. (2009) argued that students who are VI can attain levels of physical fitness that are comparable to those of their sighted peers, but they have few opportunities to make decision in their own. Additionally, past studies have reported lower levels of physical activity and a higher occurrence of obesity among individuals who are blind or VI. Table 2.9 summarizes some of the studies done with individuals who are blind or VI and their findings.

Table 2.9 *Physical Well-Being Domain*

Definition/ Indicators	Author(s)	Year	Participants	Instrument used	Findings
<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Health Status Activities of Daily Living (ADL) Leisure</p> <p>Schalock & Verdugo (2002)</p>	Haegele et al.	2017	5 adults with VI aged 18-51	Phone interviews Reflective interview notes	<p>The first study to explore the differences between Physical Education (PE) experiences in public and residential schools.</p> <p>Adults with VI who attended a residential school were more included during activities in PE classes.</p> <p>PE classes with peers with VI resulted in higher participation.</p> <p>Limited choices in general education tended to eliminate participation in PE classes.</p> <p>Teachers willing to adapt PE classes for students with VI resulted in higher participation.</p>
	Berger	2015	26 adults with VI aged 70 and older	Face to face Interviews	<p>Leisure activities that occur outside the home are related to a higher QOL.</p> <p>Transportation is a barrier to leisure activities, cultural and social events.</p> <p>Environments that are not designed for people with vision loss such as dimly lit restaurants. There was a positive relationship between engaging in leisure activities and depression.</p>
	Guarette & Smedema	2011	199 Individuals with VI	LSNS-6 CES-D-10 SWLS	<p>The higher levels of physical well-being are associated with higher levels of employment and perceived social support.</p> <p>Students with VI have lower levels of activity and physical fitness than youths who are sighted.</p>

<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Health Status Activities of Daily Living Leisure</p> <p>Schalock & Verdugo (2002)</p>	Ward et al.	2011	8 youth with VI aged 10 - 18	Low Vision Quality of Life Questionnaire (LVQOL)	<p>There is a positive relationship between physical activity levels of youth who are VI and the degree of parental protectiveness and expectation.</p> <p>Peer tutoring has a positive effect on visually impaired students in general physical education classes. Physical activities enjoyed by boys who are VI are wrestling, track and goalball and girls who are VI enjoy goalball and cheerleading.</p> <p>Quality of physical activity is an essential factor in producing health benefits.</p>
	Holbrook et al.	2009	25 adults with VI ages 18 - 60	Adaptive Physical Education (ALT – PE) Coding Sheet	<p>The study found that perceived QOL among adults who are VI cannot be predicted from physical activity level, severity of VI, or the combined influence of these variables.</p> <p>Parental involvement is crucial to maximizing participation in physical activity for youths with visual impairment.</p>
	Wiskochil et al.	2007	4 children (2 with low vision 2 blind)	Face to face interviews Surveys	<p>Children with VI have few opportunities to make decisions regarding their own physical activity because teachers and parents often make decisions for them.</p>
	Stuart et al.	2006	25 children with VI ages 10-12 and their primary parent	Face-to-face Interviews Surveys	<p>As vision loss increased (having more vision loss), parents' expectations for their children's ability to be physically active decreased, as did the children's views that physical activity is essential or useful.</p> <p>There is a link between the lack of opportunity and lower expectations for success.</p>

2.13 Material Well-Being Domain

Material Well-Being refers to the physical support to life, to the attainments that make acquisition of physical attributes possible, such as education, economic power, and good health (Ferris, 2002, p. 275). The QOL research literature for individuals who are blind or VI in the Material Well-Being domain includes both qualitative and quantitative studies (Schalock and Verdugo, 2002). While the employment rate of the general population ranges from 25% to 30%, the employment rate of the individuals who are blind is about 80% (Monson, 2009). Research in the area of the employment of individuals with VI is limited (McDonnall, 2014). It is important to note that the employment rate for blind adults is very low in the United States. The American Community Survey (2011), as reported by Miller (2014) and McMahon et al. (2013), revealed the reality of employment rates of adults who are blind. The Bureau of Labor Statistics (2013), as reported by McDonnall (2015), stated that only 31% of working-age adults with VI were employed. Also, Miller (2014) reported that only 37% of people with VI are working, and only 24% of this population are working full-time, year-round.

Additionally, Antonelli et al. (2018) found that college graduates with VI have employment challenges despite obtaining secondary education. The employment rate was 17.5% in 2015. Whereas the employment rate of the general population was about 80% in 2009, the employment rate of individuals who are blind ranged from 25% to 30% that same year (Monson, 2009). Table 2.10 summarizes some of the studies done with individuals who are blind or VI related to the Material Well-Being domain and their findings.

Table 2.10 *Material Well-Being Domain*

Definition/ Indicators	Author(s)	Year	Participants	Instrument(s) used	Findings
<p>Specific perception, behaviors, or conditions that reflect a person's perceived or real QOL.</p> <p>Indicators: Financial Status Employment Housing</p> <p>Schalock & Verdugo (2002)</p>	Antonelli et al.	2018	26 mentee-mentor pairs and 25 comparison group students with VI under age 35	Survey Face to face interview	The study identified barriers to employment: a) lack of transportation, b) employers' discrimination or negative attitudes, and c) lack of jobs.
	McDonnall	2014	158 people in the hiring position (pilot study) 85 employers	15 items attitude scale	McDonnall created an instrument to measure of employers' attitudes toward individuals who are blind as employees. Employers' attitudes are a significant barrier to employment of individuals who are blind. Employers find challenging to hire a person who is blind for the position that they most frequently fill, then a person with other disabilities, with the exception of moderate or severe mental retardation.
	Miller	2014	5 students who are blind ages 13-16	The Encyclopedia of Basic Employment and Daily Living Skills	The Workplace Expectations program enabled students to develop a better understanding of the value of appropriate workplace behavior skills. Many employers have limited understanding of the work skills of individuals with visual disabilities Schools need to develop programs that emphasize career education and workplace skills.

Indicators: Financial Status Employment Housing	McMahon et al.	2013	14 adults with VI	Survey Interview	Clients of the Vocational Rehabilitation division for the Blind are stuck in the prolonged periods of unemployment, and some of the cases have remained open for five or more years before they secure employment or stop looking for work altogether.
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In conclusion, very little has been reported on the QOL of children and adults who are blind or VI. The reason being that visual impairment is a low-incidence disability (Keiser & Herzberg, 2017). In low-incidence disability research, small sample sizes challenge researchers to demonstrate statistical significance or generalization. The history of the education of children and adolescents who are blind or VI and their QOL is important. The way we approach children's education and development will depend on what we believe about blindness and what people who are blind can achieve (Castellano & Kosman, 1997). The education of children and who are blind or VI is rooted in history and paved the way for changes in legislation that supported the education of students with disabilities in the United States.

QOL research regarding children and adolescents using the QOL domains theory as a lens found that braille literacy is critical to self-esteem and acceptance to blindness (Silverman & Bell, 2014). Family members are the most prominent source of social support, and parental involvement is crucial to maximizing participation in physical activities (Caballo & Verdugo, 1997; Wiskochil, 2007 & Kef et al. 1997), but as vision loss increases, parents' expectations for their children's ability to be physically fit decreases (Stuart et al., 2006). Additionally, children's participation in structured activities depends on family access to transportation and household income (Carlson et al., 2010). Also, there is a low quality of friendships, and social interactions of children and adolescents with VI compare to their sighted peers (Lifshitz et al., 2007). Reasons given are the inability to use nonverbal communication, difficulty acquiring social skills, and a lack of ability to read body language and emotional cues (Caballo & Verdugo, 1997). Students who are blind have very few opportunities to show competence,

autonomy, or choices in the classroom than do their sighted peers, and to make decisions because parents and teachers often make the decisions for them (Jessup et al., 2018 & Wiskochil, 2007). Usually, capabilities of the students who are VI or blind are underestimated, resulting in negative support (Caballo & Verdugo, 1997). Past studies of the QOL of adults who are blind or VI addressed individual aspects of the QOL domains, such as (a) system of supports, (b) transportation, (c) social network, and (d) employers' attitudes towards individuals who are blind or VI. The QOL for adults who are blind or VI is positively correlated with the severity of visual impairment (Renard et al., 2010) and higher social support levels. Higher levels of employment and social support are also associated with higher levels of physical, economic, and social well-being (Gurette & Smadema, 2011; Renard et al., 2010). Additionally, age, level of social support, and engaging in leisure activities were significantly associated with depressive symptoms (Renard et al., 2010; Berger, 2015).

Transportation to medical appointments or leisure activities was identified as one of the most common support activities followed by shopping and administrative tasks (Cimarolli & Boerner, 2005). Studies found that barriers to employment are associated with: a) lack of transportation, lack of jobs, and c) employers' discrimination or negative attitudes (Antonelli et al., 2018; McDonnall, 2014). Transportation is also one of the barriers to leisure activities, cultural and social events. Environments such as restaurants with dim lighting are not designed for people with VI (Berger, 2015). Quality of physical activity is an essential factor in producing health benefits (Holbrook et al., 2009). Additionally, the quality of social networks is vital for improving the functioning and well-being of individuals who are blind or VI (McIlavane & Reinheart, 2017).

The instruments used in the review of literature include face to face interviews, telephone interviews, QOL Questionnaires, surveys, and observations. Two of the research studies' main limitations are (a) small sample size and (b) generalizability of the findings (Rosner & Perlman, 2018; Antonelli et al., 2018; McDonnall, 2014; Guerette and Smedema, 2011; Silverman & Bell, 2014). Also, in a few studies, VI included both a) individuals who visually impaired and b) individuals who are blind. My research will make the distinction between the two populations. I focused only on individuals who are blind. Additionally, my study addressed all the domains of QOL according to Schalocks' QOL theory. I interviewed six adults who are blind. Interviews included questions from questionnaires, surveys, and findings of previous research studies.

CHAPTER THREE

METHODOLOGY

The purpose of this study was to understand how do adults who are blind describe their QOL. We know little about the QOL of adults who are blind, and we need to understand better how adults who are blind describe their QOL based on their own lived experiences. To understand how individuals who are blind describe their QOL, I conducted a phenomenological qualitative study. In this study six adults who are blind described the lived experiences, beliefs, understandings, and attitudes towards their QOL.

Data was collected through interviews, field note observations, documentation of demographic information, and etiology of each participant' visual impairment. The interview questions were aligned with the eight-core domains of QOL: Personal Development, Self-Determination, Interpersonal Relations, Social Inclusion, Rights, and Emotional, Physical, and Material Well-Being (Schalock & Verdugo, 2002; Table 2.3). Additionally, the interview questions are aligned with the phenomenological approach to understanding participants' experiences, beliefs, feelings, and convictions about QOL (Joseph, 2010; Glesne, 2016).

My interactions with the participants, observations, and interpretations of the narratives collected during the interviews were descriptive, adding to a detailed analysis of participants' responses. Data collected was analyzed, and patterns and themes were established. The final written report includes the voices of the participants, description,

and an interpretation of the QOL as understood by them, as well as my reflections on my subjectivity and positionality. This chapter describes the theoretical approach and study's methodology, including research site, pilot study, questionnaires developed, participants selection, participants demographic information, data collection, and data analysis.

In my study, I selected a qualitative research approach to fit my research inquiry. A detailed and complex understanding of how adults who are blind describe their QOL is most effectively done by talking directly to participants, hearing their voices, and observing where they work or live (Creswell, 2007). I designed my study, starting with the issue that I am interested in, QOL for a specific population, adults who are blind. After the literature review related to the QOL, I realized that to understand the QOL of the adults who are blind, they need to describe their own lived experiences. I had a strong commitment to this study, and I was prepared to be engaged in the time consuming and complex data analysis (Creswell, 2007). I applied several common characteristics of qualitative research (Creswell, 2007; Glesne, 2016; Moustakas, 1994) in my study. I used the following:

- a) Natural settings: Data was gathered by talking to and observing the participants one-on-one, face-to-face, or via TapeACall.
- b) Researcher as a key instrument: I gathered and collected all the data myself through interviews, field note observations, and examining documents.
- c) Multiple sources of data: I collected multiple forms of data such as interview transcripts, field note observations, and documentation of the etiologies of the participants' visual impairment.

- d) Inductive data analysis: I analyzed the data, by building patterns, themes, and categories by organizing data into abstract units of information.
- e) Participants' meanings: I was prepared for my initial research plan to change or shift after starting the interviews. My main focus remained to seek information from my participants' lived experiences, and if there was any issue or problem, to address it.
- f) Theoretical Lens: As qualitative researcher, I used QOL lens to view my study. Additionally, I used a phenomenology theoretical lens to conduct research.

Next, I describe how my theoretical views and beliefs shaped my study.

3.1 Theoretical Approach

Creswell (2007) averred that qualitative research is a process that begins with philosophical assumptions, paradigms and worldviews, and procedures involved in studying social and human problems. Grix (2002) supported Creswell's idea that qualitative research is a "process" (Creswell, 2007, p.175) and noted the importance of the interrelationship between the core components of the research process: ontology, epistemology, methodology, methods, and sources. Grix further explains that what researchers think can be researched (their ontological position) is linked to what we can know about it (their epistemological position), and how to go about the inquiry (their methodology approach).

The assumptions underlying research are both ontological and epistemological (Grix, 2002). My decision to conduct a qualitative research study is rooted in my ontological and epistemological positions. My ontological position relates to the nature of reality and its characteristics. By conducting qualitative research, I support the idea of

multiple realities and the intent of reporting/sharing them in my research. In my study, the evidence of multiple realities will include using “multiple quotes” themes based on several participants' words and different perspectives from each participant (Creswell, 2007). The understanding that individuals participating in a study view their experiences differently is supported by Creswell (2007) and Moustakas (1994). Moreover, by accessing the perspectives of several individuals of the same group about the phenomena, I suggested some cultural patterns of thoughts and actions for that group as a whole (Glesne, 2016).

My epistemological position further shaped my decision for a qualitative research study. According to Grix (2002), the focus of epistemology is the knowledge gathering process, the possible ways of gaining knowledge of social reality as it is understood to be. The most common worldviews that shape the researcher's practice and research are positivism, constructivism, advocacy/participatory, social constructivism or interpretivism (Creswell, 2007). Two contrasting epistemological positions are “positivism” and “interpretivism.” My paradigms and worldviews are based on interpretivism. Individuals describe their experiences of the phenomenon studied, and the researcher tries to make sense (or interpret) the meanings. This why qualitative research is often called interpretative research (Creswell, 2007). Additionally, Grix (2002) highlighted that researcher's ontological and epistemological positions can lead to different views of the same social phenomena.

Additionally, qualitative studies are further defined by philosophical and theoretical assumptions (Patton, 2002). My interpretative philosophical and theoretical perspectives guided the kind of study I wanted to conduct (Glesne, 2016, p. 5). As a

researcher, I relied on the participants' views of their lived experiences (Creswell, 2009), and I sought to understand the world in which adults who are blind live and work. To understand their lived experiences, I observed, asked open-ended questions during the interviews, compiled answers, and searched for patterns and themes of the participants' QOL lived experiences.

Knowledge is forever changing (Grix, 2002), and the ontological belief that tends to accompany interpretative traditions portrays a world in which reality is socially constructed, complex, and everchanging (Glesne, 2016; Creswell, 2007). This interpretative theory of human understanding is referred to as hermeneutics. As a researcher, I recognized that my own background shapes my interpretations, so I positioned myself in the research to acknowledge how my interpretations flow from my own personal, cultural, and theoretical perspective. I selected a qualitative research approach, as I wanted to allow the participants to express in their own words their lived personal experiences of the QOL as perceived by them. The researcher's role becomes "accessing others' interpretations of some social phenomena" (Glesne, 2016, p. 9). I wanted to capture the voices of the adults who are blind, therefore providing more meaningful insight into their lived experiences.

The most frequent qualitative research types in social, behavioral, and health science include narrative research, phenomenology, grounded theory, ethnography, and case studies (Glesne, 2016; Creswell, 2007). For my study, the best qualitative inquiry approach to describe the meaning of what participants have in common as they experience their QOL lived experience is phenomenology. Phenomenology is defined as a theoretical point of view advocating the study of individuals' experiences because

human behavior is determined by the phenomena of experience rather than objective, physically described the reality that is external to the individual (Cohen et al., 2007; Sloan & Bowe, 2014), In general, a phenomenological study is an in-depth inquiry into a topic, concept, or phenomenon for a small number of homogenous participants of their lived experiences (Creswell, 2007; Glesne, 2016). Grosseohme (2014) supported the idea that when a researcher wants to study what an experience means to a particular group of people, phenomenology may be the choice method.

3.2 Phenomenology

Phenomenology is concerned with the study of experience from the perspective of the individual. The primary purpose of phenomenology is to reduce individual experiences with a phenomenon to describe the “universal essence” (Creswell, 2007). According to Creswell (2007), qualitative researchers identify a phenomenon (an “object” of human experience van Manen, 1990, p. 163), collect data from individuals who have experienced the phenomenon, and develop a composite description of the essence of their experiences. Moustakas (1994) defined that the description consists of “what” they experienced and “how” they experienced it (Moustakas, 1994). Based on this perspective, understanding the reality of a phenomenon is to understand the phenomenon as it is lived by a person (Neubauer et al., 2019).

The primary role of phenomenological research is to describe rather than explain (Creswell, 2007; Moustakas, 1994; van Manen, 1990). According to Lester (1999) phenomenological studies bring to the fore the experiences and perceptions of the participants from their own perspectives so we can understand these experiences and “glean new insights” about a particular phenomenon (Neubauer et al., 2019, p. 91).

Furthermore, phenomenology has a strong philosophical component to it (Creswell, 2007). Phenomenologists believe that knowledge and understanding are embedded in our everyday world, knowledge cannot be quantified or reduced to numbers or statistics, and the truth and understanding of life can emerge from people's life experiences (Byrne, 2001). The phenomenology approach is based on the writings of Edmund Husserl (1859-1938) and the philosophies of Heidegger, Gadamer, Merleau-Ponty, and Sartre. The researcher seeks to understand the "experiences and perceptions of each participant and to examine similarities and differences across the cases" (Glesne 2009, p. 209). Philosophical views of phenomenology theorize the meaning of human experience (Neubauer et al., 2019) and share the belief that phenomenology is the study of individuals' lived experiences. These lived experiences are mindful, and the descriptions of the experiences are fundamental.

There are various approaches to phenomenology. According to Neubauer et al. (2009), they all share the definition of the study of phenomena manifested in our experience, the way we perceive and understand phenomena, and the meaning of the phenomena in our subjective experience. Some of the approaches to phenomenology include descriptive (transcendental) phenomenology, naturalistic phenomenology, existential phenomenology, generative historicist phenomenology, genetic phenomenology, hermeneutic (interpretative) phenomenology, and realistic phenomenology (Chan, et al., 2013; Creswell, 2007; Neubauer et al., 2019). The two classical approaches of the phenomenology that guide the majority of the psychological research are a) transcendental (descriptive) phenomenology and b) hermeneutic (interpretative) phenomenology (Chan et al., 2013).

Transcendental, empirical, psychological, or descriptive phenomenology is rooted in Husserl's work in the early 20th century. Husserl argued that phenomena, as perceived by individual consciousness, should be the object of the scientific study (Neubauer et al., 2019). Husserl's work is rooted in an epistemological attitude that understanding the reality of a phenomenon is to understand the phenomenon as a person lives it. According to Husserl, a lived experience of a phenomenon has features commonly perceived by individuals who have experienced the phenomenon. These features or "universal essences" can be identified and do develop a generalizable description. The phenomenon's true nature is represented by the "essence" of the phenomenon (Neubauer et al., 2019).

The researcher's challenge is to engage in the study of a person's lived experience of a phenomenon that highlights the universal essences of that phenomenon. The challenge requires the researcher to suspend his/her own attitudes, beliefs, and suppositions to focus on the participants' experiences of the phenomenon and highlight the phenomenon's essence. In Husserl's transcendental phenomenology, the researcher's goal is to achieve transcendental subjectivity – a state whereas "the impact of the researcher on the inquiry is constantly addressed and biases and preconceptions neutralized, so they do not influence the object of the study" (Neubauer et al., 2019, p. 93). This lived experience is known as Transcendental I – and is achieved through a series of reductions such as epoche (a Greek word meaning to refrain from judgment) or bracketing from previous understandings, and prior knowledge of assumptions of the phenomenon of interest. The researcher must be vigilant in his/her bracketing work, so the researcher's individual subjectivity does not bias data analysis and interpretations.

Lester (1999) supports the concept of bracketing throughout the research from data collection, analysis, and interpretation of data. Transcendental phenomenology relies on meanings as a foundation for research (Joseph, 2010) and is used in psychology and human science. Some of the researchers that have used transcendental phenomenology are Moustakas, Colaizzi, Giorgi, and Polkinghorne.

Hermeneutic phenomenology, known as interpretative phenomenology, is embedded in the work of Martin Heidegger (1889-1976). Hermeneutic phenomenology is grounded on the human experience and how human beings, as knowers of the phenomenon, live it (Neubauer et al., 2019). Heidegger was interested in human beings as “actors of the world,” so the focus is on the relationships between an individual and his/her lifeworld. The term lifeworld refers to the idea that “individual” realities are influenced by the world in which they live. Hermeneutic phenomenology studies the meanings of an individual in the world, as their experience is interpreted through his/her lifeworld and how these meanings and interpretations influence the choices that individuals make (Neubauer et al., 2019). A hermeneutic phenomenologist interprets the narratives provided by research participants in relation to their individual context to illuminate the fundamental structures of the participants’ understanding.

Since my research aimed to understand the QOL of the lived experiences of the adults who are blind, the hermeneutic approach to phenomenology can be applied to my study. I selected this approach because, first, I was equally interested in understanding the QOL lived experiences of the adults who are blind and the interpretation of the meaning of these experiences. Second, hermeneutic phenomenology recognizes that the researcher plays a role in the inquiry, and as a subject, the researcher cannot get rid of her/his

lifeworld. (Creswell, 2007; Neubauer et al., 2019; Moustakas, 1994). As a researcher, my education as a vision teacher, past experiences, and the knowledge base that led me to consider the QOL phenomenon and the lived experiences of adults who are blind are worthy of investigation.

Joseph (2010) supported that phenomenological research design allows the researcher to explore and learn about an individual's world experiences from their perspectives. By exploring taken-for-granted assumptions about their ways of knowing, phenomenology contributes to a deeper understanding of the participants' lived experiences (Starks & Trinidad, 2009). Additionally, my beliefs tend to accompany the phenomenological philosophy that knowledge and understanding are rooted in our lives and everyday world. Phenomenological quality research was the best approach for my study to answer my research question. This approach will allowed me as a researcher to explore the meaning, structure, and the essence of the QOL lived experiences of the individuals who are blind. Next, I present prior research studies, strategies, and methods employed and their contribution to my research design.

Phenomenology as a valuable tool and research strategy (Neubauer et al., 2019) is used in mental health, nursing, education, and psychology (Creswell, 2007; Moustakas, 1994). Joseph (2010) conducted a hermeneutic qualitative phenomenological study to explore the educational, vocational, and social experiences of the sixteen college-educated individuals who were visually impaired to determine how these experiences impacted them educationally, vocationally, and socially. The study's purpose was to understand college students' experiences and college-graduate students who were visually impaired. A hermeneutic phenomenological approach allowed Joseph (2010) not only to

explore, interpret her study participants' lived experiences but her own unique experiences as a researcher with visual impairment. The study was conducted over 90 days. Participants were selected using a snowball purposeful sample method. All the participants met the criteria (a) deemed legally blind by their optical physician, (b) 19 to 45 years of age, (c) college graduate or attending college, and (d) no co-morbid disorder. Participants identified were informed of the research timeline to ensure their willingness to commit to the study. During the initial meeting (Joseph, 2010), participants were presented with a summary of the study's purpose and an informed consent form. The consent form explained the study, how the study might affect the participants, and the right of each participant to cease participation at any time during the research process.

During the first thirty days, each participant was interviewed individually for approximately one hour. Participants were interviewed with the use of the Interview Guide Approach (Patton, 2002). They answered a series of questions regarding their educational, vocational, and social experiences as college graduate students who are VI. Semi-structured interviews were conducted via telephone. This approach was convenient for both research participants, and researchers as transportation was a barrier to their ability to travel but limited the researcher to interact with participants through face-to-face interviews. Interviews were audio-recorded. Additionally, Joseph asked participants to provide a one-page statement describing their visual disability.

During the second thirty days, Joseph analyzed participants' responses and identified areas that further needed clarification. A follow-up meeting was arranged for the participants identified. Data gathered from (a) interviews, (b) researcher's field notes, (c) participants' voluntary description of their disability were analyzed to identify themes

and patterns. Joseph (2010) identified four primary themes: self-advocacy, acquiring accommodations, work-related experiences, and reactions to VI. In the last thirty days, Joseph (2010) wrote the results, findings, and recommendations for the study (see Chapter Two). The hermeneutic phenomenological study approach allowed Joseph (2010) the opportunity to explore, learn, explain, and interpret the educational and vocational experiences of individuals who are blind or VI.

Guerrero (2017) conducted a qualitative study to explore how academic factors, personal and or family dynamics, and environmental or social components influence learning Braille for a student who is blind or VI. Grounded theory was employed to conduct data analysis for the study. Grounded theory methodology has played a role in developing qualitative research as an approach and an alternative to other social research, providing several tools for conducting qualitative research analysis. Guerrero identified and compared commonalities of four students who were blind or visually impaired ages 16-17 years old, by using semi-structured interviews and direct observations. According to Guerrero (2017), qualitative research explores the quality of social phenomena' experience through the use of words, images, and descriptions in attempting to answer questions based on the perception of personal experiences, referring to meanings, concepts, and definitions.

McAbee (2015) conducted a qualitative study allowing six deaf individuals to define their quality of life. McAbee's goal was to collect data directly from the participants by using American Sign Language (ASL). The study was conducted in three phases: pilot, first interview cycle, and second interview cycle. The results from the pilot study helped make changes to the interview questions. Interview questions were designed

and grouped using research by Schalock & Verdugo (2002). McAbee used a structured interview format. All the interview transcripts were merged in one document, and data were analyzed in two steps (a) word frequency analysis and (b) interpretative coding to analyze. Word frequency analysis consisted of generating a list of one word and two-word phrases for each QOL questionnaire domain. McAbee used an online text analysis program, www.textanalyser.com, to generate the word frequency analysis. Interpretative coding consisted of analyzing the data, highlighting words and phrases that repeated across the participants' questions and responses, and creating a codebook. Data were reviewed for themes that stood out to the researcher. Themes were combined to reduce their numbers, and a color-coding system for the themes was created. Next, McAbee compared the two separate analyses: the codebook with words frequency table and each theme for the codebook matched with frequent words and phrases. Each of the eight sets of most frequently used words corresponded with one or more themes from the researcher's codebook, therefore creating one set of findings. These findings became the definitions of QOL that McAbee reported as the results of the study. McAbee did not label her study as phenomenological research, but by using an interpretative approach, her study question was best answered with a qualitative inquiry approach using an interview format with open-ended questions. This study was beneficial for my research, particularly the part of QOL domains and interview questions.

Additionally, phenomenology is well suited for exploring challenges in the Health Professional Field (HPF). In their study, Neubauer et al. (2019) found that phenomenological research can broaden the understanding of the complex phenomena involved in learning, behavior, and communication in the HPF. The appropriate

application of phenomenology to HPE's research questions helps to advance understanding by learning from others' experiences. Both Joseph and Guerrero agreed that phenomenological research can broaden our understanding in the field of education and can be used to study the lived experiences of students and adults who are blind or visually impaired. As a researcher, a hermeneutic phenomenology research approach will allow me to understand, reflect, and interpret the essence of the QOL of the participants' lived experiences. Next, I describe where the study took place, pilot study results, participants selection, and how data was collected.

3.3 Research Site

The study took place in the state of South Carolina (SC), located in the southeastern part of the United States. I selected the state of SC because I live in this state and work at South Carolina School for the Deaf and the Blind (SCSDB), the state residential school. Also, I have relationships with adults who are blind across the state. These relationships and trust were created through twenty-seven years of working in the field of blindness and VI. I have taught and worked with many students and staff who are blind or VI and graduated from either the public or residential school settings and are subsequently attending college, working, raising families, or are retired. Additionally, the relationships with many TVIs across the state were very beneficial in recruiting participants for the study. The participants willingly participated and shared their life experiences. Next, I will describe how the pilot study was conducted and its results.

3.4 Pilot study

I conducted a pilot study to test the adequacy and refine the procedure and

interview questions (Creswell, 2007). I administered the questionnaires to the pilot subject, one of my former colleagues, Laura in the same way that I was planning to do for the main study (Saladana, 2016 & Glesne, 2016). Laura is a Caucasian female who is sixty years of age. Laura's diagnosis is Retinopathy of Prematurity (ROP). I have known Laura for twenty-five years, and I have a great professional and personal relationship with her. Additionally, Laura has an education and counseling background. I trusted Laura to give me candid feedback to test the questionnaires' appropriateness and capability, and to uncover any problems with the questionnaires. Laura agreed to help with the pilot study. During one of our conversations, I shared with Laura that I planned to do all the interviews face-to-face and one-on-one, but "I would prefer to do ZOOM calls because of COVID-19 and social distancing. Additionally, through Zoom, I can record the interviews." Laura offered significant input during that conversation. She shared that I need to be prepared because many people who are blind do not use ZOOM and "people who are blind like to talk on the phone."

I thanked Laura for her time and ensured that I will research how to tape the phone conversations. SCSDB information technology specialists suggested few apps. I tested few of the apps and I found the "TapeAcall" (see Appendix B), had great reviews. I tested the app with Laura. I taped our phone conversation using the app. My accent created problems for the app to fully understand what I was saying, so it took me extra time to transcribe the interview. I listened to the interview five to six times and transcribed all the interview by myself. The process was very helpful for me. Next, I will address the two questionnaires that I developed for the study and Laura's suggestions and comments about them.

3.5 The Individual Demographic Questionnaire

I developed the Individual Demographic Questionnaire for the participants that I did not have any rapport or relationship with on a professional or personal level. I designed the questions to get to know participants and to receive general information about some of the significant and meaningful experiences that impacted their lives (See Table 3.1).

Table 3.1 *The Individual Demographic Questionnaire*

<i>Questions</i>
1. Tell me about yourself. Probe: Name – I will use a fake name for the study. Do you have any preference on what I call you in the study? Probe: Age – If you are not comfortable letting me know your age, you can say, “I am in the group of 30-40, 40-50, or 50 and above years old. Probe: Gender - What gender do you consider yourself?
2. Tell me about your life trajectory – what experiences stand out to you or have had a significant impact on your life course, and why? Probe: Married, single, in relationship with someone, and children. Probe: Work, place, what do you do/did at work.
3. Describe some of your favorite education memories and challenges you have overcome.
4. Let’s talk about your blindness. What is your diagnosis? Probe: Age-on-set
5. Will you provide a written summary of your eye condition?

Laura liked the fake name suggestion for the study. She commented on question number two, “Tell me about your life trajectory – what experiences stand out to you or have had a significant impact on your life course, and why?” Laura commented that “Wording is

very stilted. What I'm trying to say it might be intimidating to some people because they probably wouldn't know some of those words.”

I suggested “Tell me about your life experiences.” Laura responded, “I love that. I think that gets to what you're looking for without the wordiness.” Laura liked the probe questions about marriage status and work. Also, she commented in the question, “Describe some of your favorite education memories and challenges you have overcome.” Laura’s comment, “I love that. That'll give you a lot of feedback.” I asked about the question, “Let's talk about your blindness diagnosis. Isn't that a good question?” Laura responded:

Very good question. And I think it gets right to the point of what you're looking for. And most blind people unless they're new to blindness, they're not going to be sensitive about talking about their blindness. They're going to be very willing to just express what the problem was.

Laura provided very useful feedback on the last question, “Will you provide a written summary of your eye condition?” Also, Laura added:

I think most people would be fine with it. Um, if anybody did have a problem, you know that they would tell you, “I don't feel comfortable writing that.” Some people are not going to have a computer. Some people are going to be able to talk about it, you know? And you might find them saying, “I can't write, I can Braille.” You may want to say, “Whatever format that you want to give it to me, it's fine, Braille or if you want to type it, if you want to write it, whatever you prefer.” It is important for you to get the information which way they prefer to give to you.

I adjusted all the questions according to the input from Laura’s suggestions. Table 3.2 represents the Individual Demographic Questionnaire, that I used in the study.

Additionally, I discussed with Laura that if any information was provided by the participants for any of the domains or indicators, I would made notes and adjust the questions in Table 3.4. Laura supported the adjustment to Table 3.4.

Table 3.2 *The Individual Demographic Questionnaire*

<i>Questions</i>
<p>1. Tell me about yourself. Probe: Name – I will use a fake name for the study. Do you have any preference on what I call you in the study? Probe: Age – If you are not comfortable letting me know your age, you can say, “I am in the group of 30-40, 40-50, or 50 and above years old. Probe: Gender - What gender do you consider yourself?</p>
<p>2. Tell me about your life experiences. Probe: Married, single, in relationship with someone, and children. Probe: Work, place, what do you do/did at work.</p>
<p>3. Describe some of your favorite education memories and challenges you have overcome.</p>
<p>4. Let’s talk about your blindness. What is your diagnosis? Probe: Age-on-set</p>
<p>5. Will you provide a written summary of your eye condition in the medium of your choice? The format can be what you prefer: Braille, typed or e-mailed.</p>

3.6 QOL Interview Questionnaire

I designed the interview questions based on the review of the literature, specifically of McAbee’s study (2015), “How do deaf individuals define their quality of life?”, Shalock and Verdugo’s (2002) book “Handbook on Quality of Life for Human Service Practitioners” and the Quality of Life Questionnaire (QOLQ) instrument

developed by Keith and Schalock in 1993. As I mentioned in the literature review, many quantitative studies (Schalock & Bohan, 2003; Guerrette & Smedema, 2011; Rodriguez et al., 2009) have validated the work of Dr. Schalock in the QOL. My research approaches QOL through a qualitative approach. Based on this lens, my interview questions are aligned with the phenomenological approach to provide knowledge of the lived experiences, beliefs, and attitudes toward QOL based on Schalock and Verdugo's (2002) factors, core domains, and the indicators of the QOL (See Table 2.3). I designed open-ended questions for the questionnaire and had probes to assist the interviewee.

Table 3.3 represents the QOL Interview Questionnaire that I designed for the study.

Table 3.3 *QOL Interview Questionnaire*

Factors	QOL Domains	Interview Questions
I N D E P E N D E N C E	Personal Development Education Personal Competence Performance	How did your visual impairment impact your childhood? Tell me about your educational experiences. Probe: Elementary, Middle, and High school Talk about what you did after high school. Describe what you do/did at work. In what ways do you continue to learn as an adult?
	Self - Determination Autonomy Personal Control Goals Personal Values Choices	Describe your independence. Talk about some activities for which you feel are your responsibilities. Tell me about your support systems. Name a few of your personal goals. What choices do you have when you are most able to make decisions? Describe what you value in your life.
S O C I A L	Interpersonal Relations Interactions Relationships Support	Talk about the relationship and support you receive from your family. Probe question: Transportation Describe your relationship with people with whom you socialize or work. Tell me how they support you. How satisfied are you with your relationships with other people?

P A R T I P A T I O N	Social Inclusion Community integration Community roles Social Support	Talk about how you are involved in the community. Tell me what your community offers for individuals who are blind or visually impaired. Describe some of the services in the community that you access for support. Tell me about your resources for social support. If I were to talk to one of your friends, what would you want them to tell me about you?
	Rights Human Rights Respect Dignity Equality Legal Citizenship Access and due process	After graduation (high school or college), what did you know regarding rights, equality, and dignity? What have you learned since then regarding rights, equality, and dignity? Describe how you want your friends or people in your community to interact with you. What do you want them to say about you? How are you treated in terms of equality? Have you ever had an experience where you were mistreated? Describe. Tell me about your experience with voting. Tell me about your experiences with services from the Commission for the Blind.
W E L L B E I N G	Emotional Well – Being Contentment Self – Concept Freedom from Stress	Defining community as the people you interact with frequently, such as friends and people from church, work, or gym, please describe your community. Tell me about some of the benefits you get from having friends in your community. Talk about how you are essentials your community. Describe your overall emotional well-being.
	Physical Well – Being Health Status Activities of Daily Living Leisure	Describe your overall health and fitness level. Talk about how this is related to your vision. How do you access your health provider? Describe some of the activities do you do daily. Is there anything in the area of health and fitness that you would like to access but cannot? Explain.
	Material Well Being Financial status Employment Housing	Describe your work environment and its accessibility to you. Describe your home or the place where you live. (For example, do you rent, own your own home or live with someone?) Defining financial stability as paying bills, having an emergency fund, and saving for retirement, please describe your financial status. Is there anything else you would like to add?

Laura cited the question, “In what ways do you continue to learn as an adult?” as an “awesome question” but suggested simplifying it “How do you continue to learn as an adult?” Also, Laura shared her own experience that having friends in her life has enhanced the quality of her life:

I mean, that's in my own life. That has been one of the things that have made the quality of my life. So awesome is to have friends and to have people in my life that I know are real true friends. And, I hope that folks will be honest and really tell you the truth about what they're feeling and what they are truly, you know what their lives are really like, and not try to paint a picture.

I liked Laura’s comment “be honest” and made a note on my field notes. There were two questions (1) Describe your relationship with people whom you socialize our work and tell me how they support you, and (2) How satisfied that are your relationship with other people? I asked Laura about her suggestions to keep both of the questions or only one.

Laura suggested:

Well, I think it's important to keep both. I really do, the reason I think it is because if they are feeling like they don't have friends and don't have people in their life, you need to know that as to why the quality of their life is as it is. You know, if they tell you, nobody ever talks to me, nobody spends time with me, I'm very lonely or whatever, they've told you that the quality of their lives is not very good. Then you have a reason for that. You need to ask both; I think it's important. I do.

Laura responded that I will get lots of the examples and I will have no problems on the question “How are you treated in terms of equality?”

Laura added that:

Unfortunately, in a lifetime, any time there is a difference in someone, and we're all different, but nobody really recognizes that blindness is just a difference. It's not an adequacy. I always told the kids; blindness is just different. It doesn't mean that you're less than means that you're just different, but people don't recognize that, unfortunately, and so there's a lot of pain and a lot of hurt, and you will probably hear some of that pain and some of that hurt in the examples that they give.

I discussed with Laura that I left the questions about physical and material well-being at the end of the questionnaire and the participants may chose not to answer them if they are uncomfortable. Laura stated that physical and material well-being are personal, but they are important. She approved all the questions on both of the domains.

Furthermore, she added:

Material well-being is connected with stability, security and safety and all the things that make us comfortable, have to do with our environment, everything that we are has to do with our stability and safety. Shelter is the biggest that gives the stability and well-being feelings of security. So, I think as long as you know you're asking it in a general way that would that should not make people feel uncomfortable about answering that question. But just ask them, you know, to just let you know if there's anything that that is not clear to them that you'll be glad to clarify. And, I think just making them feel comfortable about your questions. And they've obviously said yes to it, or you wouldn't be in their home or talking to them on the phone. You know, there's something they've agreed to, so it would be

they've already given you permission to ask them questions. So, it should be a very positive experience, I hope for you.

I shared with Laura that of the six participants for my study, I would prefer that three of the participants to be individuals that I do not have any rapport of professional or personal relationships. Additionally, I shared that I was a little nervous about how the interviews will go with them. Laura gave me great advices and a lot of encouragement for the study.

Just be open and kind. And just say, you know, this is this is my doctoral study.

I'm wanting to talk with you today. Just introduce yourself a little bit and make them feel comfortable. They're going to be more than happy to talk with you.

Once you open the conversation and you're very personable, you're very welcoming, giving and kind. And once you establish a rapport with them and help them feel comfortable about talking with you and the way you can do that is just the way you naturally do it. today. And, I think you'll be very effective because you are very friendly and open; just talk kind to them and you'll do really well.

Another piece of advice that I used with every participant was clarifying the questions.

You can say at the beginning in your introduction too, is if there are any questions that you don't understand or I need to clarify, please let me know. And that way, people won't hesitate to say I don't understand what you're asking.

I adjusted the questions on QOL Interviews according to the input of the pilot study.

Also, if the participants provided any information for the QOL domains or indicators, I made notes and adjusted the questions in Table 3.4 which represents the final version of the QOL Interview Questionnaire.

Table 3.4 *QOL Interview Questionnaire*

Factors	QOL Domains	Interview Questions
I N D E P E N D E N C E	Personal Development Education Personal Competence Performance	How did your visual impairment impact your childhood? Tell me about your educational experiences. Probe: Elementary, Middle, and High school Talk about what you did after high school. Describe what you do/did at work. How do you learn as an adult?
	Self - Determination Autonomy Personal Control Goals Personal Values Choices	Describe your independence. Talk about some activities for which you feel are your responsibilities. Tell me about your support systems. (Family, friends, etc.) Name a few of your personal goals. What choices do you have when you are most able to make decisions? Describe what you value in your life.
S O C I A L P A R T I P A T I O N	Interpersonal Relations Interactions Relationships Support	Talk about the relationship and support you receive from your family. Probe question: Transportation Describe your relationship with people with whom you socialize or work. Tell me how they support you. How satisfied are you with your relationships with other people?
	Social Inclusion Community integration Community roles Social Support	Talk about how you are involved in the community. Tell me what your community offers for individuals who are blind or visually impaired. Describe some of the services in the community that you access for support. Tell me about your resources for social support. (NFB) If I were to talk to one of your friends, what would you want them to tell me about you?
	Rights Human Rights Respect Dignity Equality Legal Citizenship	After graduation (high school or college), what did you know regarding rights, equality, and dignity? What have you learned since then regarding rights, equality, and dignity? Describe how you want your friends or people in your community to interact with you. What do you want them to say about you? How are you treated in terms of equality? Have you ever had an experience where you were mistreated? Describe.

	Access and due process	Tell me about your experience with voting. Tell me about your experiences with services from the Commission for the Blind.
W E L L B E I N G	Emotional Well – Being Contentment Self – Concept Freedom from Stress	Defining community as the people you interact with frequently, such as friends and people from church, work, or gym, please describe your community. Tell me about some of the benefits you get from having friends in your community. Talk about how you are essentials your community. Describe your overall emotional well-being.
	Physical Well – Being Health Status Activities of Daily Living Leisure	Describe your overall health and fitness level. Talk about how this is related to your vision. How do you access your health provider? Describe some of the activities do you do daily. Is there anything in the area of health and fitness that you would like to access but cannot? Explain.
	Material Well Being Financial status Employment Housing	Describe your work environment and its accessibility to you. Describe your home or the place where you live. (For example, do you rent, own your own home or live with someone? Defining financial stability as paying bills, having an emergency fund, and save for retirement, please describe your financial status. (Give the participants the choice to respond or not) Is there anything else you would like to add?

I adjusted the questions on both questionnaires according to the input of the pilot study.

My study involved human subjects so I obtained IRB through UofSC Columbia. Next, I will explain how I selected the participants for the study.

3.7 Participant Selection

Blindness is a low incidence disability, so the population from which I drew the participants was very small. My study involved human subjects, so I obtained IRB through UofSC Columbia. Since the data collection process requires an in-depth study of human experiences of “a small number of homogenous participants” (Glesne, 2016 p.

290), phenomenological studies do not have a large number of participants (Eddles-Hirsch, 2015). Large samples are not necessarily needed to generate rich, in-depth data. Starks and Trinidad (2007) supported the small number of participants knowing that an individual can generate hundreds or thousands of concepts. Data from only a few individuals who have experienced the phenomenon and can provide a detailed account of their lived experiences might suffice to uncover its core element. Regarding their lived experiences and perceptions, no one in the world has better knowledge than the participants themselves (Chan et al., 2013). Typical sample sizes for phenomenological studies range from one to ten persons (Starks & Trinidad, 2007).

I used a purposeful sampling strategy to recruit participants for my study. The process of participant selection consisted of two parts, general and specific. I selected the participants beginning with general criteria (a) a diagnosis of blindness, (b) between the ages of 19-65 years old, (c) no additional disabilities except visual impairment, and (d) willingness to participate in the study. Participants were selected through contacts with SCsDB, the SC Commission for the Blind, the AER (Association and Rehabilitation of Teachers with Visual Impairment), and the AER List Serve. I received e-mail responses from many TVIs and O&M specialists in SC with suggestions of individuals who may be good candidates for the study. I sent e-mail messages to potential participants and invited them to join the study (see Appendix C).

I compiled an initial pool of sixteen individuals who responded. First, I contacted all potential participants via phone or e-mail. I explained the objectives and purpose of my study and the study's timeline to ensure their willingness to participate. (Joseph, 2010). I ensured the participants' confidentiality of their identity and their right to leave

the study during the research process. Second, from my list of potential participants, I identified only those individuals who were blind. I had six participants that have some vision. I thanked all of them personally for contacting me and for their willingness to be part of the study. Two of six candidates recommended two other participants that ended up being in the study. Third, I narrowed the candidates' list according to age criteria (19-65 years old) and willingness to participate in the study. Creswell (2007) suggested to select individuals who are accessible and willing to provide information. I had six participants in the age group of 40-50 years old. Third, I selected six participants according to gender: three females and three males. I choose the same number of males and females because I wanted to have the perspectives of the QOL lived experiences from both sexes. Fourth, I selected participants who have first-hand knowledge of the QOL lived experiences and were not hesitant to speak and share ideas. Fifth, one of the participants was selected as a parent of a child with VI. Sixth, I selected three participants that I had a rapport with through years of working in the field of VI and three participants that I did not have any relationships or rapport with. The rationale for purposefully selecting the participants generally and then is explicitly supported by Patton (2002). According to Patton (2002), this purposeful sampling focuses on selecting information-rich cases, illuminating the questions under investigation, even from a small number of participants. Next, I explain how I collected the data and the timeline for the study.

3.8 Data Collection

The data collection of the study changed due to the COVID-19. I had planned to collect all the data with one-on-one, face-to-face interviews. Due to COVID-19, data were collected with one-on-one, face-to-face, or phone calls with each participant. I

conducted all the interviews with each participant alone and followed these guidelines (a) gave participants time to finish a question before moving on the next one, (b) used minimal probes, (c) asked one question at a time, and (d) monitored the effect of the interview on the participants (Smith, 2009; Smith & Osborne, 2012).

To answer my research question, “How do adults who are blind describe their QOL?” I collected and analyzed the data replicating Joseph’s study (2010) data collection timeline. Data was collected over 90 days, including (a) interviews, (b) field note observations and memos, and (c) documentation of the etiology of the participants’ visual impairment.

During the first 30 days of the study, I conducted an initial meeting (Joseph, 2010) with each participant via phone. I explained the consent form and study’s timeline to each participant. My priority was the three participants that I did not know. I wanted to create rapport with them, so I made two more phone calls to all of them. I gave each participant the choice of interview location, one-on-one and face-to-face interviews or via phone. I was very content that three of the participants that I did not know expressed the desire to meet face-to-face for the interviews. I was invited to two of the participants’ homes and arranged picking up one from his home to go to a restaurant. I traveled nine hours to meet one of the participants and three hours to meet the other two. The meetings were used to obtain a signed written consent form (Appendix D) for the study and complete the personal demographic questionnaire (Table 3.2). The interviews were conducted one-on-one, face-to-face (keeping social distance and wearing masks) with three participants, and via phone with the others. All the interviews were recorded through a voice recorder or TapeAcall. As a backup for face-to-face interviews, I used a

second voice recorder to record the interviews. The interview data was collected through a semi-structured interview technique using open-ended questions that I developed in advance (Table 3.4).

One-on-one and face-to-face interviews were the best choice for my interviews because it gave me an opportunity to create a rapport with the participants and observe their body language and O&M skills. During the interviews, I took observational field notes, and I listened carefully to what participants say or did, observed interactions, and addressed any questions. I described the purpose of the study to the participants and how the data collected will be kept and used. Using a semi-structured interview technique, I was guided by a set of questions (see Table 3.2 and Table 3.4), but the participants' interests and concerns determined the interview progression. I was very flexible to add more time or more interviews, according to each participant.

The second 30 days were used to finish the interviews with all the participants. I analyzed the participants' responses to identify areas that needed clarification (Joseph, 2010). Two other phone interviews were arranged with the participants identified. From a phenomenological approach, after the interviews are completed, the researcher utilizes the data obtained to determine the essence of the participants' experiences (Creswell, 1994; Joseph, 2010). My data collection are the transcripts of in-depth interviews, which provided knowledge and information about the participants' lived experiences related to QOL. The other part of the data was my observation field notes. I took detailed notes, listened carefully to what participants said and did, observed interactions, and addressed any questions or concerns that they had. I described the environment and setting of the restaurant to one of the participants and observed their body language and O&M skills.

Additionally, I asked all the participants to provide a one-page written summary (Joseph, 2010) of their visual impairments' etiology in the medium of their choice. The written summaries served as another part of the data collection. The last 30 days were used to analyze the transcripts, write the study results, findings, and recommendations (Joseph, 2010).

3.9 Data Analysis

The data analysis was based on participants' transcript interviews, field note observations, researcher's memos, and each participants' visual impairment etiology documentation. Additionally, I will present themes and subthemes that emerged from the data analysis. The data analysis starts with the participants' demographic information. All the names of the participants are pseudonyms. I asked all the participants to give me a pseudonym to use in the study to keep the confidentiality of their participation. All the participants except one took time to come up with a name. Some of them chose the name of a flower, favorite season, or the favorite time of the day. Steve was the only one who responded quickly and said that if he can name himself, his name will be Steve. The six participants are listed alphabetically. The information was collected from the conversations, interviews, and the documentation of the etiology of their visual impairment provided by participants.

3.10 Participants Demographic Information

Carolina Girl

Carolina Girl is a forty-three years old, Caucasian female; her diagnosis is Leber's Congenital Amaurosis. Carolina Girl grew up with a very supportive family and with peers who were VI from grade school to high school. After she graduated from public

high school, she went to a small college to get her Bachelor's degree and earned her Master's in Social Work from a university in a large urban area. She graduated with honors from both. Carolina Girl works for NFB and she is a single parent of two young school-age children. Carolina Girl walked independently inside and outside her house. She uses both a cane and a guide dog.

Dahlia

Dahlia is a Caucasian female, thirty-three years old. She is the first person in her family with a visual disability. Dahlia's diagnosis is Leber's Congenital Amaurosis. She grew up with a very supportive family in a very rural environment, with a sister as "free range kids" doing horseback riding, biking, and waterskiing. After she graduated from public high school, Dahlia attended a university in an urban area and got a Bachelor's degree in political science. Dahlia lives in neighborhood very close to downtown. Dahlia loves animals, gardening, and hiking. She works for a nonprofit organization that helps people with disabilities to find jobs.

Daytime

Daytime is a Caucasian male, fifty-one years old; he was born blind due to detached retinas. At the age of four months, his family found out that he was blind because he was not responding to light or funny faces. He is married to "his high school sweetheart" and has an adult son. Daytime walked to my car independently using a white cane. He used the cane the whole time that we were together. He walked independently to the restaurant where we met. He is a Social Security Administrative Judge.

Phoenix Jackson

Phoenix Jackson is an African American male, fifty years old. Phoenix Jackson

diagnosis is Glaucoma. Phoenix Jackson lost his vision when he was 13 years old. He is married and between him and his wife have four children and thirteen grandchildren. Phoenix assists the teachers in implementing their lesson plans and teaching and reinforcing work with technology and Braille. Phoenix's diagnosis of VI is Glaucoma, he was born with it, and it is congenital. He had pretty much normal vision in his left eye. As he got older, Glaucoma began to onset which, cause the deterioration of his vision. He went to SCSDB when he was about 13 years old.

Steve

Steve is a Caucasian male in the group of 50-60 years old. Steve's original diagnosis of VI was macular degeneration, and according to Steve, his diagnosis did not make sense because the vision that he had was in the center of his eye. Four years ago, Steve did some more in-depth testing, and his visual impairment is dystrophy. Steve grew up in rural SC and the school district that Steve graduated from was labeled impaired. Steve is the first-generation high school and college graduate in his family. Steve holds a Master's and Ed. S in leadership. Steve works at a state agency in SC and supervises staff who work with children who are blind and VI. For twenty-five years, Steve has worked as an adjunct professor at the graduate schools of few universities in SC. Steve was the only kid who was blind in the neighborhood and the only person in his family who is blind. Steve was raised in a country church and learned to play the organ at a very young age. Steve started leading the worship service at his church at seventeen years old and has continued to do that for thirty-five years.

Summer

Summer is an African American female in the age group of 40-50 years old. Summer's diagnosis is congenital Glaucoma and Cataracts. Summer was born with vision problems but had fairly decent sight when she was young. Summer had her first cataract surgery when she was six months old, and had multiple surgeries after that. Summer lost her vision when she was fourteen. Summer attended both public school and SCSDB. She graduated from SCSDB and attended a Postsecondary Program for adults who are blind or VI. She owns her own business and has employed people who work for her. Summer is married and between her and her husband they have three children. Summer has a son who is VI and he is attending college. Summer is her favorite season, so she picked that as her pseudonym name. I used all the information gathered from the interviews, etiology of blindness or VI that participants provided and to create a table with the demographic information (See Table 3.5).

Table 3.5 *Demographic Table*

<i>Name</i>	<i>Age</i>	<i>Gender</i>	<i>Race</i>	<i>VI</i>	<i>Education</i>	<i>Marital/Status</i>
Carolina G.	43	F	C	LCA	Master's Degree	Single
Dahlia	33	F	C	LCA	Bachelor's Degree	In relationship
Daytime	51	M	C	Detached Retina	Law Degree	Married
Phoenix J.	50	M	A	Glaucoma	Associate Degree	Married
Steve	50-60	M	C	Dystrophy	Ed. S Degree	Single
Summer	40-50	F	A	Glaucoma/Cataract	Post-Secondary Program	Married

Note: A: African American, C: Caucasian, LCA: Leber's Congenital Amaurosis

I analyzed the data using Interpretive Phenomenological Analysis (IPA).

According to Smith et al. (2009), IPA does not include a single step of data analysis. It

contains the following characteristics (a) movement from what is unique to a participant to what is shared among the participants, (b) description of the experience which moves to an interpretation of an experience, (c) commitment to understanding the participant's point of view, (d) psychological focus on personal meaning-making within a particular context.

After each interview, I first looked at the field notes and wrote a memo for my interview experience with each participant. Second, I transcribed all the interviews. It took between six to eight hours to transcribe each interview. I shared the transcripts with all the participants and asked for feedback. I made a few changes and clarified a few questions. Third, I created a file for each participant that contained voice recording, transcribed interview and analyzed interview. I saved all the files in a thumb drive and secured the thumb drive in a locked file cabinet. Fourth, I deeply immersed myself in the data via listening, reading, re-reading, writing, and re-writing (Neubauer, 2019; Sloan & Bowe, 2014). Data analysis consisted of identifying themes, phrases, and descriptions in the participants' transcripts. Next, I revealed themes and patterns from the participants' responses and transcriptions and developed a set of themes and descriptive comments from the interview transcripts. I looked for "commonalities among participants in addition to what is unique about each individual" (Joseph, 2010, p. 118). Common themes and patterns were used to establish experiences most frequently shared by participants in the study. By applying a hermeneutic phenomenology approach, I examined the text to reflect on the context to discover something "telling," "meaningful," and "thematic" (Sloan & Bowe, 2014). I "wrote" a story that captures the important elements of the lived experiences of the adults who are blind.

3.11 Looking for Themes

I listened to each interview four or five times and I read and re-read the transcripts to become familiar with them. The number of my participants was small enough for me to retain an overall mental picture of each participant's transcript (Smith & Osborne, 2012). I divided each page of the interview into two columns. I went through the whole interview for each participant, making notes to the column on the right. I treated all the transcripts as potential data (Smith & Osborne, 2012), and I made no attempts to omit or select particular passages for special attention. I used the right side of the margin to note down anything interesting or significant to participants (Smith & Osborn, 2012). Some of my comments were attempts to summarize, some were preliminary interpretation to document emerging themes and titles (Smith & Osborne, 2012). Table 3.6 is a part of the Steve's interview that illustrates how I looked for themes.

Table 3.6 *Steve's Interview*

<p>Thank you. So, what I think help to change the perception of people around here is, by the time I was 17, I was leading worship at church on the organ, and I have done that for the past 35 years. So, I was always perceived as the kid that could, rather than the kid that couldn't. I've won several trophies over the years with the youth program, Um, with my knowledge of the Bible, which I got from reading Bible stories that Miss MH, my teacher of the visually impaired, recorded for me at her voice during my young years.</p> <p>My mother was a reader and love to read until her death. And she read to me many times as a child. Whatever book I wanted, just she would read, um, we would sit in a</p>	<p>Steve learned to play organ at a very young age.</p> <p>Leading the worship at his church at age 17</p> <p>Steve perceived as the kid that could rather than the kid that couldn't – Self-Advocacy</p> <p>Steve won several trophies over the years with the Bible youth program. - TVI going above and beyond her job</p>
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big chair together, and I was a little skinny kid. You I know you can't imagine that, but I was and she would, uh, she would read to me. And, so books, learning and reading were always high on my list.	Steve's mother read aloud to him - Growing up with supportive family
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I proceeded through each transcript following the interpretative process and I compiled a final master list of themes. I listed all the emerging themes according to three factors of QOL a) **Independence**, b) **Social Participation**, and c) **Well-Being**. After I constructed all the major themes from the data, I started writing about them one at a time (Saldana, 2016). Some of the themes had their own subthemes. For example, the “Role of the Teacher of Visually Impaired (TVI)” theme had following subthemes (a) TVIs support for parents, (b) TVIs impact in the participants’ life starting at a very young age, and (c) service delivery.

Eight themes were related to **Independence** (1) Growing up with Supportive Families, (2) Educational Experiences, (3) Self-Advocacy Skills, (4) Impact of VI in their Childhood, (5) Role of the TVI, (6) O&M Skills, (7) Independence, and (8) Learning as Adults. Eight themes were related to **Social Participation** (1) Support Systems, (2) Asking for Help, (3) Participants’ Community, (4) Advocating for Individuals who are Blind or VI, (5) Transportation, (6) Attitudes towards Blindness, (7) Voting, and (8) Equality. Five themes were related to **Well-Being** (1) Emotional Well-Being, (2) Health and Fitness, (3) Accessibility of Work and Home, and (4) Employment, (5) Material Well-Being. Table 3.7 list the themes that were identified through data analysis. Themes were selected according to richness of the data of particular passages which highlighted the theme (Saladana, 2016; Smith & Osborne, 2012) and how the themes helped to illuminate aspects of the other participants were taken into consideration

(Weaver-Hightower, 2019). After I discussed each theme and their subthemes separately, I began reflecting on how they were connected and woven together (Saladana, 2016 & Weaver-Hightower, 2019).

Table 3.7 *List of the themes*

Independence Factor	Social Participation Factor	Well-Being Factor
<ul style="list-style-type: none"> • Growing up with Supportive Families • Educational Experiences • Self-Advocacy Skills • Impact of VI in their Childhood • Role of the TVI • O&M Skills • Independence • Learning as Adults 	<ul style="list-style-type: none"> • Support Systems • Asking for help • Participants' Community • Advocating for Individuals who are Blind or VI • Transportation • Attitudes towards Blindness • Voting • Equality 	<ul style="list-style-type: none"> • Emotional Well-Being • Health and Fitness • Employment • Accessibility • Material Well-Being

The common thread for all the themes and subthemes was QOL theory. All the themes are part of the QOL factors and domains. According to Saladana (2016), how the researcher perceives and interprets what is happening in the data depends on what type of filter cover the lens and from which angle the researcher views the phenomena. By analyzing the data through a phenomenological analytic lens, I highlighted experiences and perceptions of each participant and examined similarities and differences among them (Creswell, 2007; Glesne, 2016; Moustakas, 1994).

The next step of the data analysis was translating the themes into a narrative account and looking for connections between the themes and the literature. I used

Table 3.7 as the basis for an account of the participants' responses using verbatim extracts from the transcripts to support my case. In the next chapter, I discuss the findings through the Independence, Social Participation, and Well-Being factors and the themes and subthemes that emerged during the data analysis.

CHAPTER FOUR

RESULTS

In this chapter, I provide the stories and lived experiences shared by the participants related to Independence, Social Participation, and Well-Being factors.

4.1 Independence Factor

According to Schalock and Verdugo (2012) the Independence factor includes a) Personal Development Domain (Education, Personal Competence and Performance), b) Self-Determination Domain (Autonomy, Personal Control, Goals, Personal Values, and Choices). The common themes that emerged from the Independence Factor are (1) Growing up with Supportive Families, (2) Educational Experiences, (3) Self-Advocacy Skills, (4) Impact of VI in their Childhood, (5) Role of the TVI (6) O&M Skills, (7) Independence, and (8) Learning as Adults.

Growing Up with Supportive Families

The most significant commonality of the six participants was growing up with supportive families. Daytime shared on his interview that his family taught him to be independent. Additionally, he emphasized that people who are blind are capable of doing things that sighted people do:

My mother taught me how to wash clothes when I was a child and how to wash dishes. My parents thought that blindness was such a terrible thing that if they

taught me how to be, how to be independent, like washing clothes and taking out the trash. But it's somehow would make me less blind. What we did not know at that time, almost all blind people are capable of doing those things. It's just that most people don't know to teach a person how to do it because they just assume, well, they're blind. I'm going to have to do it for them.

Steve's story:

My parents never adopted the attitude that I could not or should not do. Their attitude was I needed to carry the same weight in the house as my brother. We all hated dishes, and Mom made us all wash dishes. I could do laundry by the time I was in middle school, not only for myself but for the entire household. We were always responsible for cleaning our rooms, keeping our bed linens changed, and cleaning bathrooms. All of that I got at home.

Carolina Girl shared in her interview that she had a very supportive family growing up:

I had a very supportive family. My parents divorced when I was three. And, they put their differences aside to make sure that I had the balance and there was no excuse of why I can do something. No, no, no! I can't do that. They will not have it! [LAUGH] You need to do it! [LAUGH]. Because I'm blind didn't exist. No, it didn't exist. And it does not let you get away with anything. And it doesn't exist with my kids that we work with now. I mean, they can't come and say that to me, you know, at children's camp in our ST program. They can't do that. So, um, I think that was huge, that if I couldn't do it, I couldn't use it, because I was blind. I just found other ways to do it. Um, it was thinking outside of the box, there was no box, and I never fit in a box.

Summer appreciates that her mother motivated her to be independent. My field notes indicate that her voice trembled after she said “my mom”:

My mom, [PAUSE] she pushed me just as hard as she would push her other kids. And I really value that. Because I feel about her being as hard as she was on me has made me a better person today to be independent and always motivating myself and pushing myself to do things that I normally would not do, out of my comfort zone.

Phoenix Jackson shared in his interview that his parents were very supportive after he lost his vision:

I would say my parents were a huge, huge support and really trying to teach me how to do things in a different way so I can maintain that independence. Um, so they pushed me pretty well. It wasn't very hard to push me because I've always been the type to want to be able to do things as much as I can on my own. Um, so, you know, my mother and I have three brothers, so my mother, she was always said to me and all of my brothers, “You need to learn how to cook, you need to learn how to clean, you need to learn how to take care of yourself. Do your own laundry because you cannot go through life thinking someone else is going to do it for you. You need to know how to do it.”

Steve shared the memory of his mother reading aloud to him at a very young age:

My mother was a reader and loved to read until her death. And she read to me many times as a child. Whatever book I wanted, just she would read, Um, we would sit in a big chair together, she would read to me. And, so books, learning, and reading were always high on my list.

Parents are a crucial source of emotional and social support (Kef et al., 1997; Joseph, 2010). The above statements of the participants provided evidence that family support is critical for children who are blind or VI. Additionally, Guerrero (2017) found on her study that parent commitment consisted of investment of time, finances, and support. Next, I will present educational experiences that participants shared in our interviews.

Educational Experiences

All the participants' educational experiences included experiences from grade school, high school, college, and graduate school, that were both positive and negative. One of the commonalities among all the participants' educational experiences was getting a good education. As Dahlia said in her interview, "A good education increases your chances for success in the future." Two of the participants have the educational experiences of both public school and SCSSDB, the state residential school. Two tools that helped the participants to become successful are learning to read and write in Braille and Independent Living Skills (ILS).

As Dahlia stated in her interview:

Even though I was in class with everybody else the rest of the day, just getting Braille instruction was instrumental in helping and giving me the tools that I needed at that time for a successful outcome. And so, that goes to the quality of education and, ultimately the quality of life. Because of a good education, using that foundation that you need to increase your chances for success in the future.

Two other participants, Daytime and Carolina Girl, contributed their success to learning to read and write Braille well at a young age. They both emphasized the need to teach students who are blind and VI to learn Braille when they are young. Carolina Girl contributes her success to Braille. She stated “Things that have really contributed to my success is that I read and write Braille very well and efficiently, and I've learned since I was five that is huge for me.” Daytime compared the experiences of the sighted children and children who are blind or VI:

Think about what we do with sighted children before they start school; we read to them. Look at the book that we're reading. They see the pictures, they put their fingers on the letters, and point the things that they see on the page. And, it's just as important for blind children. And the thing is about children who have the smallest vision while growing up; there's a significant chance of that vision will deteriorate because the age just like with a sighted person, um, whose vision deteriorates as they get older, even if they don't become blind. Your vision only gets worse during your lifetime.

As Carolina Girl emphasized in her interview it is important to start learning to read and write in Braille when you are young:

Young, absolutely, learning young, because that's when kids learn their letters and things like that and learning Braille. And I know some people can't because they're, you know, they go blind, later or whatever. I think whether you have a lot of sights, and are half-partial versus if you're blind, you need to learn Braille, just in case, yeah, it's easier to learn when you're young, then trying to learn it when you are not young.

Guerrero (2017) also supported learning Braille when children are young but she stated that instruction must focus on basic reading process and not just braille code. Summer shared that learning ILS skills at SCSDB helped her later in life:

I learned a lot of ILS skills as far as cooking and cleaning and being independent to live on my own. And people always tell me that I keep my house very neatly and clean. Also, I like to cook for people. When we have dinner parties, they always want me to cook certain dishes. I love to cook for my family for Thanksgiving and Christmas. Everyone ends up at my house to eat. So usually, I am cooking for 40 or 50 people. It helped me tremendously to learn those things because it gave me ideas how to raise my kids.

One of the educational experiences in high school that impacted the Carolina Girl's life was her trip to South America:

As a junior in high school, for a month, I traveled to South America. There were 11 of us from my high school and our competitor high school, and it was an honor to be chosen. And it was a complete immersion. We went to school there stayed with a family. But that was an event with a really impact. Oh man, I mean, to the point that I went on to college and finished with a minor in Spanish. It impacted me that much.

Summer vividly recalled in our interview the traveling clubs at the SCSDB:

One of my favorite things that I really enjoyed when I was at the SCSDB is that we used to do a lot of traveling. We had different clubs where we go to different places to talk about drugs and alcohol. It was called the “Just Say NO Club.” We also had another club called “Blind Pride”, where we went around to the different

schools in the area to teach students and staff about being blind and how we learn to live in society.

Two of the participants have the educational experiences of both public school and SCSD. Phoenix Jackson was one of the first students from SCSD to be mainstreamed in the public school:

One of my favorite educational memories is attending SHS (local high school) because it allowed me to be among sighted peers. But, also to a large group of sighted peers to show them that just because I am visually impaired does not mean that I don't have the same interest, the same drive, or the same educational level or intelligence as they do.

Summer valued her educational experiences through the public school and SCSD.

Summer stated: "I value the fact that I had the experiences of going through the public school system and going to the Blind school in Spartanburg."

Carolina Girl summarized that a very supportive TVI and peers who were VI were important to her educational experiences:

There were two other blind children, at the same school. I grew up with one of them from five years old. And then another girl joined us when we were in the fourth grade. So, there were three of us. It is quite rare in the same school. So, I would say that made it: having a very supportive teacher of the visually impaired, active teacher and the visually impaired peers.

Research supports that commitment of the TVI in education and learning impacts educational experiences of the students who are blind or VI (Guerrero, 2017; Joseph, 2010; Silverman & Bell, 2018).

The subtheme of college experiences and graduate school was apparent in five of the six participants. All the five participants described their college experiences, the importance of self-advocacy skills, personal determination, self-motivation, positive and negative impact of teachers in the college experiences. Five of the six participants have experienced college and graduate school. The sixth participant had training in a post-secondary program for students who were blind or VI. Phoenix Jackson, as noted in my field notes, got excited when he described his favorite educational memories:

College. I truly enjoyed going to college because it was just a different independent experience. But also, it was the infancy of them starting to put in the accessibility office. So, it was kind of baby steps of them trying to figure out what works and what doesn't. So, I was kind of like, um, a guinea pig during that particular time at the community college.

One of the participants, Carolina Girl, shared that getting a Dog Guide in college was a life-changing experience and improved her confidence:

College was great! It was small enough, but it was big enough. I was by myself in a room only because I had a guide dog. I got a guide dog between my freshman and sophomore years of college. So, I was a cane user. I mean, not to say I'm not a cane user now because I use a cane when I need to. But I got a guide dog. And that was another life-changing experience for me. It really opened me up socially. It opened me up more confidently. I mean, I had the dog, and now I had those cane skills. Yeah, because I went through my whole freshman year without a dog. Miserable, but I did. And, it was that for me to gain that confidence. And so, when I got a dog, after having a cane for so many years, it just opened my world

of people actually getting to know me as a person. I mean, they could easily, how they can't say, "Hey, how's your cane doing today?" But they can say, "Hey, I really like your dog or what is your dog's name?" or whatever, and conversation feeds that will be the icebreaker. And since I'm so shy anyway, so shy [LAUGH]. It was a life-changing experience to have a dog. And my personality just came out much, much more.

Steve's story speaks to the influence and impact that teachers have in the life experiences of their students:

The other life-changing thing that was negative for me was in my senior year. One teacher would tell us, sometimes when she was ranting in the classroom; the teachers did by then, that we were from an impaired school district and we were going to have a very difficult time, that we were going to struggle in college because we didn't have what we needed. That made a huge impact on me because when I got to college for my first year, um, my high school best friend and I were roommates, and we both sat in this woman's English class. And I remember the night before my first class, we had a deck of cards, and we played Gin rum all night. Both of us were terrified to go to class the next day. He graduated number three in his class, and we were afraid that we weren't going to be good enough to be able to do what needed to be done. Those were just, those were big, memorable experiences for me that were not positive, uhm, growing up.

Steve explained the importance of learning to take notes in high school. He did not learn how to take notes in high school and that affected his academic performance in freshman year in college.

Steve's story:

I didn't excel academically in freshman year in college as I did in high school. I never learned to take notes until I go to college because all I had to do was sit in the classroom and listen to it go by and I could do it. That doesn't work in college. I transferred to FM college. And let me assure you that if you think it did not work at USC, it definitely did not work there.

Carolina Girl shared her educational experience in college and graduate school and emphasized the support of the Disability Service Coordinator:

I graduated (college) with honors and said, you know what, I'm going to grad school. If I don't go now, I will not do it later. I went to grad school at a university in an urban area, and got my master's in social work. And there again, I had a great Disability Services Coordinator. I pretty much did most everything on my own, getting my readers they happen to be people in my class. They became lifelong friends of mine. And, and we would, I mean, they have to do the work anyway, you might as well get paid to do it. You know, you're having to read it anyway. And I remember sitting, you know, in the horseshoe in the grass, reading or doing our work, and so, and a lot of my friends were nontraditional students and a little bit older than me. And so, two years and there, I even went to summer school. And again, I graduated with honors.

Daytime shared that he was one of those people who was always a big self-advocate, and was very aware of his rights:

I knew the administration in high school, the principal, and the assistant principals, and in college. I had an opportunity to get meet the university

president at the University of South Carolina and with the campus of 20,000 or 30,000 people with all of the college and graduate students and faculty everything there not everybody got to meet the president. I went as part of a group of four or five people and the commissioner at that time of the Commission for the Blind. And he had gotten to know me because I went and made a presentation before the governing board 30 years ago or so and argued that if you want to go to law school and you were blind student, the agency should not only provide financial assistance for you to attend undergrad, but they should also provide assistance for you to go to law school. Because if your career objective was to be a lawyer, it wasn't enough just to graduate from college. There I was 21 years of age making a presentation at the governing board of the Commission for the Blind. And at that time, I think the Commissioner, uh, notice me, and he probably thought, well, this guy, he can talk. And, so when he was meeting with JP, who at that time was the president of the USC, I think, they were attempting to establish a relationship with USC for some cooperative initiative, I went as a Carolina student.

Guerrero (2017) supported the young adults who are blind or VI need to be able to communicate their academic needs to disability support service. Carolina Girl shared her educational experience in college and graduate school and emphasized the support of the Disability Service Coordinator:

I graduated (college) with honors and said, you know what, I'm going to grad school. If I don't go now, I will not do it later. I went to grad school at a university in an urban area, and got my master's in social work. And there again, I had a great Disability Services Coordinator.

Joseph (2010) found out on her study that there is a lack of services that were available to students with disabilities on college campuses Carolina Girl's advice to students who are VI and Blind that are planning to go to college highlights the importance of the support from the disability coordinator.

What I really try to teach and help our students now is get to know that disability support who, you know, is the service coordinator. You got to know. And if they don't have one on campus, you probably shouldn't go there.

Five of the six participants described the importance of self-advocacy skills, personal determination, self-motivation, in their college experiences. Next, I will discuss the theme of the self-advocacy skills.

Self-Advocacy Skills

Self-advocacy was one of the identified themes in area of independence. Dahlia expressed in her interview that it is hard to advocate for yourself when you are in grade school:

School, especially grade school, was really very challenging and not for the reasons that you might expect, you know, people, naturally go to being bullied or not having access to academic materials, not getting the accommodations that you need. It was none of that. It was silly things like we had to get to school almost 45 minutes early. And I never could find my friends. And so, in grade school, it's hard to advocate for yourself and be like, "Hi, my friends, you know, will you please shout across and draw attention to yourself in this huge common room to let me know where you are?" No, they're not going to scream out. Yeah, I'm sitting at lunch, just I would find a spot and hope that the people that were there

the last time would be there this time. So, I don't know that I ever made long-lasting relationships in grade school, probably for that very reason.

Participants shared in their interviews that their self-advocacy skills and self-motivation played a role in their success in life. Two of the participants emphasized that self-advocacy skills helped them to become successful in college.

Carolina Girl's experience:

I pretty much did most everything on my own, getting my readers they happen to be people in my class. They became lifelong friends of mine. And, and we would, I mean, they have to do the work anyway, you might as well get paid to do it. You know, you're having to read it anyway. And I remember sitting, you know, in the horseshoe in the grass, reading or doing our work, and so, and a lot of my friends were nontraditional students and a little bit older than me. And so, two years and there, I even went to summer school. And again, I graduated with honors.

Dahlia shared that her self-advocacy skills changed when she got to college. Dahlia stated "Once you get into college, you know, we have a chance to kind of reinvent ourselves. And, you know, I advocated differently. And it was just apples and oranges." The research supports that developing self-advocacy skills early in life helps individuals who are blind or VI to become successful in life (Joseph, 2010, Guerrero, 2017). Participants shared their life experiences and how self-advocacy skills helped them to reach their goals. Dahlia expressed in her interview that it is hard to advocate for yourself, especially if you are in grade school. Steve shared on his interview how he applied himself academically:

So, I was always perceived as the kid that could, rather than the kid that couldn't.

My parents did not insist on education for me, but I was internally motivated or self-motivated. And, I looked at how we lived, which wasn't bad. We had a roof over my head, plenty of food to eat. But we didn't have the newest car, and the latest clothes and the best house and some of the finer things of life wasn't part of what we had. And I just always thought I want to live better than this as an adult; I want to live differently from how I watched my parents live. And, so I applied myself academically. I graduated number six out of a class of 187 even though we were labeled an Impaired School District.

Summer emphasized in her interview that she has a lot of motivation:

I have a lot of my motivation. Okay. I've always had the attitude to not let something beat me. If it is something that I really want to accomplish, I will put my mind to it, and I will eventually figure out a way to do it to my best ability.

Another subtheme that was noted by three of the participants was the transferability of self-advocacy skills from high school to college or work. Guerrero (2017) supported this finding on her study. Carolina Girl summed that up by saying:

When we got to college, we had the skills to be able to advocate for what we needed. We may not have had someone to Braille all our textbooks, or, you know, someone to talk to our teachers for us or anything; when I got to college, I could be my own voice. I could be that voice to advocate for myself.

Daytime shared his experience to “learn to speak up” and self-advocate at a young age:

I was only 22 years when I began meeting with the United State Senators at that time, and other members of the congressional delegation and the federation. Luckily, the delegation that I was with gave me a chance to talk about legislative

initiatives that the NFB of the nation supported. So, at a very young age, learned I learned to speak up, you know, whatever level, um, would it be the state level or, uh, federal level, um, or by school campus. You know, just stick up for yourself and as I say in high school [PAUSE] I was a blind kid who also could speak up. I will tell you what I thought. But if they said something I disagreed with; I would tell them why. And sometimes they got the final word, you know? But sometimes, uh, I got them too, uh, to change their mind.

Carolina Girl supported that and stated that was very young when she learned to advocate for herself:

I absolutely did. I learned very young to advocate for myself. You have rights.

From a personal and professional experience, you may have been educated, but this is life experiences, life learning, lifelong learning.

Phoenix Jackson emphasized that to excel you have to be self-driven and self-independent:

You have really had to be diligent whether you're in high school or college, because, you know, books weren't just readily there when they switch or change books and things of that nature. So, you know, we didn't have Braille printers just to spit out, you know, hundreds of pages of braille, you know, a minute. So, you really have to be self-driven and self-independent to really excel.

The the idea of being self-driven was supported by Steve. Additionally, he shared his experience of advocating for himself with the counselors at the Commission for the Blind: "I was always able to self-advocate. I never really had to, um, go above a counselor anything to get anything that I needed. But, I had great counselors."

Guerrero (2017) identified in her study that self-advocacy was one of the areas of independence. Also, having confidence and a strong desire to be independent was a common finding among the participants of her study.

Impact of Blindness

All the participants experienced a different level of vision loss and they shared experiences of how blindness and VI impacted their childhood. The experiences that they shared are positive and negative. Dahlia remembered reading Harry Potter's book as a child: "I always had a low vision as a child. When Harry Potter's book first came out, I could sit in like perfect lighting on a perfect day, and I could kind of read it very slowly, at a snail's pace, read it." Additionally, Dahlia shared some of her memories of going Trick or Treating in her neighborhood:

Trick or Treating was always a nightmare, like, let's go run around in the dark and interact with strangers. And yeah, and figure out where the candy bowl is. Little stuff like that that at the time seemed really big and, you know, sad for kids, but like, you make it through it, and you're fine.

My field notes indicated that Dahlia had a positive demeanor "you are fine" "you make it" even when she was talking about some not so positive experiences. Daytime reflected on his interview on the importance of using hands to develop fine motor skills for children who are blind or VI:

Using your hands, for example, to stack blocks, tie shoes, put things together, work with electronics. Whatever the case may be a child when they're putting blocks together or they start by putting shapes and a little ball where there'd be a round hole or square, or you practice putting the shapes in the right places. So,

children are learning at a very young age how to use their hands, and they are developing signs and gross motor skills. But if you're a blind kid and all you're allowed to do is sit there, and every time you try to move, somebody wants to do it for you. You don't develop those skills. Do you? Ever. If you consider a butterfly if you help the caterpillar to break its cocoon. If you break the cocoon, a butterfly will not know how to fly correctly. So, it has to make its wings stronger by getting out of the cocoon on its own.

Participants shared some educational experiences growing up that were not very positive. My field notes indicated the participants showed a lot of emotions when they talked about the experiences. Steve's story supports that public school teachers' attitudes towards blindness or VI can affect educational experiences and impact children who are blind or VI for life:

I had in fifth-grade a white lady teacher and an older or middle-aged black lady. And I won't call their names, and that white lady refused to have me in her classroom because of the equipment and materials that I used. She just said: "I do not want to take responsibility for it." My TVI, who followed me all thirteen years K through 12, said to my parents and the school administration, she can't do this. She has to let him in there. However, I'm afraid if we do that, he's going to have a very miserable year. So, I was the only kid that did not change classes into fifth grade. I stayed with that wonderful middle-aged black lady my entire, um, fifth-grade year. Um, so that was very... [PAUSE] you can tell. I can still remember it very clearly.

My field notes indicated that Steve's voice was trembling and paused and Daytime shared that he got picked on as a child: "Also, as a child, children can sometimes be mean. They pick on each other. And, so as a blind kid, sometimes I was the person that got picked on." As Lifshitz et al. (2007) stated in their study children who are blind or VI succeed in adapting to life despite the risk of adversity.

Role of the TVI

Some of the subthemes expressed by the participants were the role of TVI and the impact in the participants' life starting at a very young age, TVI support for parents, service delivery, and TVI purpose for students who are blind or VI to achieve goals. One of the participants, Carolina Girl, shared in our interview:

I would say a big thing that has impacted my life, the teacher of the visually impaired. I had one from when I was five in kindergarten until I started phasing out in high school but still had access until I graduated from high school.

My field notes indicate that Dahlia spoke with admiration for her TVIs: "I had two TVIs, Mr. A first and then Mrs. M, who is a saint. Mr. A was awesome, but Mrs. M. was the best."

Another participant, Steve, shared his appreciation for his TVI and how TVI guided his parents. My field notes indicate that I had the experience meeting Steve's TVI a few years back when she was honored at one of the Vision Summits:

She was a marvelous lady. She served as my TVI throughout K to 12 grades, and she was an absolutely wonderful Southern Baptist lady. She served as an organist at her church, and she provided untold support for my parents and for my

teachers. She came to our home even before I entered kindergarten. So, I guess Child Find, or whatever was at work. There was no early intervention at that point. That came years later. But she knew about me, and she came to our home. And, so my parents always relied on her, and they listened to her. So, when my little brother got a tricycle, I got a tricycle. And when he got a bicycle, I got a bicycle. I had some usable vision at that point in my life. And she provided that guidance.

Summer, as parent of son who is VI, shared her experience with her son's TVI. My field notes reveal that she got excited when she talked about Ms. T:

When Ms. T (TVI) came along, she jumped on it and got it done, she was a blessing. She is not just a vision teacher; I tell everybody she was an angel. She was a blessing! We tell each other, "Hey, friend." We still out of school a year and a half, almost two years over and me and Ms. T, we still talk to each other. My son and his girlfriend came down to visit in October around my birthday, and we called her because we know she had to meet her. So, we met up, obviously for my birthday dinner to meet my son's girlfriend. Oh, yeah! We love her, I tell you she was a lifesaver for my child.

Daytime shared in our interview his early education memories and the experience being one of the first student who was blind in public school:

I was one of the first students that began school as a Braille reader. The President had just signed what became known as IDEA; at that time, it was the EAHCA Act, and it required the public schools to accept students that were in special education programs. And, so I began first grade, and the officials where I started school

didn't quite know what to do, but at that time, they sent me across district lines to an elementary school where a blind lady worked throughout the day, and I would see her for a portion of the day. You know, the myth was already out there that somehow if you're a Braille reader, you can't spell as well. She said, well, you should learn all the contractions in grade two Braille. You should learn what those contractions mean. She wouldn't have it. She did not put up with, uh, making up, uh, an excuse as to why a person could not spell just because they went Braille. One of subthemes in the service delivery by TVI was teaching how to read and write in Braille. All the participants read and write Braille proficiently. Five of the participants learned Braille early in life. Daytime shared his earliest memories served by his first TVIs and that he was fortunate to have a resource instructor who was proficient in Braille:

I can't remember how much time, but it might have been an hour or so, and she taught me to read the write, Braille. So, I begin in first grade, um, with Braille and, even things like spelling. And, uh, since I've gotten older and I've been a user, I have to agree with her (TVI) because audible learning is not the same thing as reading and writing in Braille. Uh, I would say as far as the analogy is concerned, Braille reading and writing is closer to reading and writing print than so, at least in Braille. You're learning how to punctuate, you're learning about paragraphs, and you also learn how to spell. Because if you work hard enough at Braille and you read it every day, you learn what the combinations of characters, what they stand for, even when you're reading Grade Two Braille. So that was a very important component of the educational process as I grew up, And, even

though I relocated to another state at a young age, I was fortunate enough to have a second resource instructor who also was proficient in Braille.

Steve shared his experience learning Braille later in life:

She (TVI) did not introduce Braille instruction early on, and my vision did deteriorate in middle school. She did introduce Braille, but I was such an established print reader and could still read. I did not learn the code at that time.

Another subtheme in service delivery of TVI was the collaboration between classroom teachers and TVI. Steve shared during the interview how his TVI advocated on his behalf with other teachers:

She [TVI] ran interference with teachers. You may not believe this, but I was timid as a child and often shy, so she had to provide some intervention. I know she did with a couple of teachers, one of them being a middle school PE teacher. I did everything he said to do. And, he gave me a C on the report card, and she said: “How is this? How is it that he has a C?” Well, he said, he didn't do everything that all the other kids did, you know. She said it is your job to design a program for him. That means the same goals, but you got to get there in a different way. After that, I think I could have sat on the bench and done nothing, and I would have got a straight A.

Another subtheme in the service delivery by TVI was adaptation and accessibility of print materials. Carolina Girl shared in her interview that how the TVI made everything accessible:

When I was in school, if there weren't any materials, she (TVI) would get them brailled, she would have them produced. We had a Braille embosser. And so, any

diagrams, she would use puff paint or even whatever that I don't know what that thing is called, where you punch the dots. And then you can, it's a little rubber pad rise stylus thing so that we could use that. Everything was super accessible. Also, if I wrote the math problem, she would transcribe it for the teacher. I remember taking notes, and she would make us take notes. We write it on a piece of paper, and then we'd have to cut them out and then put them in the correct order. Let me tell you, I never took notes like that ever in my life. But I remember that so vividly. I mean, she taught us how to write our names in cursive. And, um, you know, how did the print alphabet look alike, even though we weren't going to be print readers. And I wasn't going to be a print reader. But, you know, we have to learn to sign our names we have to live in a sighted world, you know, so we knew those skills. I learned those skills. And so, you know, that was huge, that was a big part of my life.

As the participants explained in their interviews, TVIs played a big role in developing self-advocacy skills. They shared that the TVIs helped them to become independent. My field notes revealed that Carolina Girl's face lighted up when she talked about her TVI:

So, I mean, she was hard. She gave us a lot of grief. But she was one of those teachers that you needed. And it was it was tough love, tough love. I knew she cared about my success and things like that. Sometimes, I didn't like what we had to do, but I feel like that was a part of our success, our independence. Starting in high school, we wouldn't go every day; we would go a couple of times a week, and by the time we were senior, we did not go at all unless we needed her. So, we were independent.

Steve shared similar experiences as Carolina Girl did with his TVI. Steve's TVI worked herself "out of job" by his senior year.

Steve's story:

She (TVI) worked her way out of a job. So, the last year of high school, she just showed up and was there. Sometimes she was reading the paper, but she did very little in terms of accommodation for me at that point because the whole idea of a TVI you do need to work yourself out of a job by their senior year. And, so she did follow that.

Guerrero (2017) argued that the TVI still needs to work in ECC skills. The ECC affords an extension beyond the core curriculum of reading, writing, and calculation. Five of the participants viewed the role of the TVI reduced as part of their independence.

Additionally, two stories shared by Dahlia and Steve are examples of the TVIs going above and beyond their duties to ensure that students achieved their goals not only in education but in leisure skills, too. Dahlia shared in our interview how she got the PE credit to be able to graduate with a diploma from high school.

Let me tell you a cool story about Mrs. M (TVI). So, in order to graduate from high school, you had to have a PE credit, and you had to pick between archery, badminton, soccer, line dancing, like all these ridiculous things and I could not do, you know at this point, I could just see it playing out. I was like, Okay, so I'm going to sign up for line dancing and archery, and I'm not going to be able to really do any of it, and it's going to be awkward, and I'm going to be singled out, and I'm going to dress out, and you know have to like put on all these gym clothes

and then sit on the bleachers. And so, we were like, hey, do I like actually have to do this? And they said, Yes, you do and all the way up to the district level. Yes, you have to do it. And, so Mrs. M, in a past life, had been a PE teacher. And she went and got recertified and said, Okay! I'm your PE teacher now. And we did bowl, which I could do. And, we went to Rec Center, and I learned different swimming strokes. We went to Dream Riders, and I got to walk with the horses and, you know, not be on the horse, but actually help facilitate therapeutic horseback riding. And that's how I got my PE credit because somebody said that's not acceptable.

Steve's shared that, "I've won several trophies over the years with the youth program, with my knowledge of the Bible, which I got from reading Bible stories that my TVI recorded for me at her voice during my young years."

Guerrero (2017), found that TVI commitment was evident in-service delivery, commitment and efforts to prepare the students for the future. This is supported by experiences and stories shared by all my participants.

Orientation and Mobility (O&M) Skills

O&M skills play an important role in the independence factor. Those skills are taught by specialists who are trained to teach to individuals who are blind or VI how to travel safely, efficiently, and independently in various environment. Summer dedicates her independence to learning O&M skills early in life: "I am pretty much very independent as far as my mobility, learn a lot of mobility all the way up until I graduated from high school. And, I am very good with that." One of the participants, Daytime,

refused to use a white cane in high school. As he mentioned in his interview, he had very minimal instruction in cane travel after graduating from high school:

I didn't carry a cane in high school, even though I went to a school with some well over 2000 students. And, I had the smallest amount of eyesight, but, um, I just didn't want to be seen walking around with a cane for some reason. And I remember the stories of how I run into people or walked outside. I remember, on a couple of occasions, I would run under the breezeway. There'd be these little, um, pillars that held up the roof of the breezeway. So, one time I was walking down a sidewalk, and there was a little breezeway kind of had a little jet, I didn't know the thing jutted, and I ran into the pillar. And, at that time, the man (O&M specialist) who was there to work with me on cane travel kind of smile and said: "Would you like a cane?" And, I remember saying I don't need a cane. I was all mad, but I didn't need a cane! I was sitting there with my forehead, a scrape on it and probably bleeding a little bit, and I told him I didn't need a cane. But, when I got to college and that urban area with cars going up and down the streets, I decided that I wanted to live. I began using a cane at 18 years old and I continue to use it.

My field notes indicate that Daytime walked from his house to my car independently using a white cane. He used the cane all the time that we were together. Additionally, Daytime got out of the car and walked independently to the restaurant where the interview took place. In one of my memos, after the interviews I noted that all the participants in the study are trained to use white canes. Also, two of the participants use guide dogs to travel and walk independently.

Dahlia got her first guide dog few days prior to interview:

That was something that I really had to weight on as I was trying to decide whether or not I wanted to get a dog. That was a huge consideration. It is already weird enough to be me, am I going to add an extra layer on top of it? And when I was talking and doing research and trying to pick a school and talking to different people who I know have dogs, I would ask them question “Is it worth?” And everyone said yes, with no hesitation. It’s going to be extra, but it will be worth it. She is my first one [LOOKING AT THE GUIDE DOG AT HER FEET] I think to get to a place where she and I are working together as a team as opposed just managing the puppy that she still is and we will get there. She is a good girl!

My field notes specify that Dahlia’s guide dog stayed at her feet very quiet the whole time of the interview. Steve emphasized that it is important to have O&M skills and quoted one of his NFB friends “You need to have the skill, and then it's up to you to choose how you do things. And nobody can criticize you if you walk side guide versus using the cane, as long as you have the skill to do either.”

Independence

Schalock and Verdugo (2012) identified independence as an important factor on the QOL of the individuals with disability. The below statements made by the participants stated how they described and valued their independence. Phoenix Jackson described his independence as:

I am very independent. I truly, even though I'm married, the one thing that I always tell people, she’s, my wife; she's not my chauffeur; she's not my maid. So, I always try to have alternatives. Sometimes she doesn't like to go where I like to

go. So, I'm very thankful that we have Uber and Lyft, and I do use these things. I do use Uber. I do use Lyft. Technology really helps play a big part in independence because we're able to pay bills online, shop online. I can go on to the Walmart app and doing Walmart orders and, you know, catch an Uber, or if she's available, take me by to pick it up. I don't have to really wait on someone else now to be able to do things, so I feel like it's increased my independence, and I feel like I've gained more independence because of all of these services that are available instead of decreasing. I think some people have a tendency to decrease their independence if they get a husband or wife or someone. And they just totally rely on that person where I like to have alternatives. My wife appreciates that about me, too, because she doesn't feel like she always has to be on call.

Carolina Girl is very proud that she lives independently, my field notes reveal that she smiled really big when she talked about her new car:

I live alone, and two children live with me. I mean, I independently live by myself. Shop, whether it's through apps or going to the store, I travel, whether it's through, you know, personal driver, or Uber or Lyft. So, I bought my first car at the beginning of this year. The first vehicle, never had a vehicle until January. The researcher [SURPRISED], "You bought your own car?" Carolina Girl "Bought my own car, and it is in a garage, you can see it." But, you know, that was independence for me. I mean, I have to get a driver, but it's much easier to find a driver. Buying a car has been independence, for me. I have young children that are very involved, from scouts to baseball to gymnastics, they're involved.

And it's so much easier to leave the stuff in the vehicle and is take it instead of going back and forth between people's cars.

Daytime defined independence in his interview as:

Independence to me means that you can do what you feel like doing whether or not someone else feels like helping you with it. The reality is, if you teach a blind person how to wash clothes or take the trash out or get from point A to point B, they have just as much potential to be independent as anybody else does. But most people, in trying to be helpful, they actually prevent the blind person from being as independent as they can. So, I lived by myself in two big urban cities for a while and, I did my own laundry and caught either Uber or Lyft or a taxi and found a way to get groceries, which usually involved ordering them online and having it delivered. So, in terms of independence, I am independent, independent as anyone else. Only I get information from four senses instead of five.

Dahlia explained in her interview that like other people with vision loss, she had to develop her independence:

I think I'm independent and stubborn [LAUGH]. And it's something that I think that I had to develop. And I suspect that you know, the other people with vision loss had to develop. The world will say that you sit right here, and I'm going to go do it for you, and you wait, and then I'll come back. And then I'll tell you the next movement that you're allowed to make. And they don't say it like that, but that's again, that's what they mean. Um, and so we have our option is to, you know, very quickly get into that, learned helplessness. Or to say, actually, no, I'm not going to just like, sit here, actually I'm going to go with you. [LAUGH] I don't

drive but if I want a soda, I got to go walk and get it. If I want some pretzels, I got to go walk and go get it. If I want to go to the grocery store, like I've got a call an Uber or get it delivered. It's, if I want, what I want, and what I need, then I don't have a choice, I got to go do it.

Summer emphasized in her interview that she is very independent. Summer stated: "I am very independent for me and my family. Pretty much every day I clean up my home, cook, wash clothes and I do everything as a sighted parent or wife would do."

Steve shared in his interview that he relies heavily in technology to manage his life: "I have a personal laptop, a personal desktop, and iPhone. I don't get into every new gadget that comes out, but I use my devices and learning how to connect all that together to get access." As Daytime, my participant said in his interview, "I am independent, independent as anyone else, only I get information from four senses instead of five."

Learning as Adults

Learning as an adult was one of the questions that the participants have many commonalities such as reading, professional development, technology, and hobbies. The younger participants rely on podcasts, networking, and different apps. The following statements are the participants' answers to the question, "How do you continue to learn as an adult?" Carolina Girl emphasized reading and professional development:

I continue to learn as an adult [LAUGH] read, read, read and read some more.

Professional development, like you, know conferences, things like that. Also, I'm networking with other professionals.

Daytime admits as an adult that he doesn't know everything, so he continues to learn.

Well, everybody's trying to continue to learn every day; if you stop learning, I guess your mental faculties perhaps would suffer over time. So, I try to admit as an adult that I don't know everything. And if there's somebody that I meet who knows more about something than I do, I'm not too proud to ask them to, uh, like me sometimes younger people, no more than I do, but with age, uh, hopefully, you gain wisdom, and, um so I hopefully between to be wiser every day as well. But I definitely still try to learn as much as I can every day. Um, hopefully, as long as I live, I'll continue learning more things, for example, about playing guitar. I've been playing guitar since I was a child, but I don't know everything there is to know about playing guitar, but if I meet someone who's a really good guitarist, I will ask him, "Give me some pointers."

Dahlia shared in our interview that she loves podcasts, loves to read, and travel to different conferences for work:

I love podcasts. But not like the like murder mystery ones. I like the science ones, or the "Stuff You Should Know" ones. I like to read. A lot of professional development, it's kind of built into the job. I enjoyed it. Pre COVID-19, one of my favorite things to do was to get on a plane and go to a work conference and just like deep dive into something for a week.

Phoenix Jackson stated in his interview that he wants to keep up with the new technology and young people:

Honestly, I continue to learn as an adult because of just the way society changes for young people. I mean they have so much more access to information than we did when we were young, and honestly, a lot of them know so much more,

whether good or bad, than we do because they have access to technology and things like that it gives them an advantage that sometimes I don't think they realize.

Steve shared in his interview that he got some good training in ILS skills but he shared that the best lessons he got in ILS were from one of his neighbors who was blind:

Um, one of the most helpful people that I ever met was a lady named RB who died about three years ago. She was an alumnus of SCSDB. I lived down the street from her in WC in the early nineties for about four years, and I learned more about how to manage a house, cook and so forth from that lady than I ever learned from all of the training that I got. I got some good training, but I learned more from her about ILS than I realized, this is what you do and this is how you do this. She had a huge impact on my life. She was totally blind, high school graduate, and she was just tremendous.

Summer shared that she continues to overcome challenges and improve her cooking skills: “One of my biggest challenges was I did not know how to how to fry food. I used to be very terrified, and I've overcome that fear. And now I'm able to fry food, bake and also cook on the stove.”

The question “How do you continue to learn as an adult?” was unique for this study. All the participants shared their experiences how they continue to learn for work or leisure skills. In summary, the eight themes that emerged from the data analysis related to **Independence** are (1) Growing up with Supportive Families, (2) Educational Experiences, (3) Self-Advocacy Skills, (4) Impact of VI in their Childhood, (5) Role of the TVI, (6) O&M Skills, (7) Independence, and (8) Learning as Adults. Next, I discuss

the social participation factor and the themes and subthemes that transpired through data analysis.

4.2 Social Participation Factor

The social participation factor includes the Interpersonal Relations Domain (Interactions, Relationships, and Support), the Social Inclusion Domain (Community integration, Community roles, and Social support), and Rights (Human Rights, Respect, Dignity, Legal Citizenship, Access, and Due Process) (Schalock & Verdugo, 2012). The eight themes that emerged through the interviews for the social participation factor and its domains are (1) Support Systems, (2) Asking for Help, (3) Participants' Community, (4) Advocating for Individuals who are Blind or VI, (5) Transportation, (6) Attitudes towards Blindness, (7) Voting, and (8) Equality. Next, I discuss the eight themes that emerged through the data analysis and lived experiences of the participants related to each theme.

Support Systems

All the participants shared support systems that they have in their life. Phoenix Jackson specified his support system:

I think I have a pretty good support system just with friends and family because the one thing I always try to do is not make myself a burden to friends or family. And that's why I always try to have alternatives even with coworkers. I think by being upfront and honest in that note and allowing people to be honest, it makes it more comfortable with me. So, I think they're more willing to just offer their help.

Carolina Girl shared her support system as:

I have an amazing support system, from church, work to family, friends. I rely more and more on friends and family because I find that sometimes you give them little benefits, you know, pay them, buy them lunch you know those kinds of things I never want to take advantage of somebody's time or kindness. Sometimes I do find that by people, you know, they forget that it takes time. It takes somebody kindness; it takes some nice gas. And, you know, if you offer them some money, if you buy them lunch, if they turn that down, that's OK. But you should at least offer, and I don't think they understand that etiquette of, you know, that they just assume well, they are offering, so they should just do.

Summer's support system:

My support system, my husband is very, very supportive. I have several friends, and they very close to me, here where I live. I don't have any of my family here. Besides my kids, um, and my sister, she moved up here. I have a really great support system with a lot of friends, my husband, and my kids. They support me.

Daytime shared that his family support was and still is important to him:

So, I grew up with a sighted girlfriend and later my wife. We were high school sweethearts, starting when I was late 10th grade and all through 11th and 12th grade. And, she's very helpful. And, it's very handy to have a set of wheels, and she drives, Um, so to get us to where we need to go. But then, when I left SC for a while, she and my son stayed in SC. Well, I have friends. It's like everybody else would, and, uh, they all that song "Lean on Me" comes to mind by Bill Weather. So, there is a need, whether you are sighted or blind, to have, um, people who

support you and believe in you. And, but you also have to have the ability to, um, get what you need. Uh, when you need it without having to inconvenience somebody else. Um, because it may not always be somebody around to help you with something.

Steve's interview emphasized that using technology is good but having someone to help with sorting mail saves time:

My support network has shrunk a little bit as I've gotten older, because some of them have died off or they've gotten even older than I am, and they're not as able. Uh, I do have a friend that is pretty close to me. He does a lot of driving for me. And a lot of, um just assisting with reading things and that kind of things that are in print. I can still use technology to scan all of that but if I've got a week worth of mail, it'll take me, and I were to go through it. Whereas my friend can help me go through it in 10 minutes. So, it does come down to a time factor.

Dahlia's support system includes her partner, her sister and friends:

My sister lives 30-45 minute from here but she works here in the city. So, she is in the city frequently. She is the one that gets me out socializing where sometimes, I would much rather like being holed up here in the house. My partner and I will go to the grocery stores when we need to do a big run. If I need to go to the vet, he has a truck that lives in my driveway and so if we need to go somewhere, we can do that.

The research of the literature indicates that support from friends and family is key to QOL of people who are blind or VI (Joseph, 2010). The statements made by my participants and life experiences that they shared supported that.

Asking for Help

One of the common themes on the data analysis was how sensitive was for all the the participants to ask for help. My field notes indicate that all the participants responded to the question and they all have in common that they are very sensitive to other's people time. Phoenix Jackson shared in his interview that before he makes any decision, he researches to see if it's something that he can do with minimal assistance or minimal interference from someone:

I'm a big researcher about stuff instead of just jumping into it because if it's going to entail me having to have someone else's time for me to do it. I'm very, very, very conscious of other people's time. I feel like all visually impaired people need to be very conscious and sensitive of the people's time because they are doing you a favor. You know, when you do ask them for assistance for something and that you kind of need to have your ducks in a row, whether it's going grocery shopping or anywhere else.

Carolina Girl stated on her interview that it is hard for her to ask for help. But, as Carolina Girl emphasized that it is no different form a sighted person asking for help.

She stated:

I am not good to ask for help. That is stressful! You know, if I need help, um, maybe I will, but this has nothing to do with the independent agent asking for help, advocating. And because the sighted person would ask for help for something if they needed something. This is no different.

Daytime shared on his interview that asking for help it may inconvenience someone else.

Additionally, as an adult who is blind you have the ability to get what you need:

So, there is a need, whether you are sighted or blind, to have people who support you and believe in you. And, but you also have to have the ability to get what you need it without having to inconvenience somebody else. Um, because it may not always be somebody around to help you with something.

Next, I discuss the theme of the community where the participants work or live, and how they describe their own community.

Participants' Community

The researcher defined community as people the participants interact with frequently, such as friends and people from church, work, or their gym. The participants were asked to describe their community. Carolina Girl's community is church, friends, and friends at work. Dahlia's community is her partner, friends from work, friends from college, and family. According to Dahlia, it is a small number, "but they are good." They are people that she works with, went to college with, people that she has worked with in the past and has developed relationships, and even she does not work together anymore, they still stay in touch.

Summer shared that she loves to meet different people in the community:

It really is great to have friends in the community and even like going to the gym and meeting different people in the community. I've learned a lot about, you know, being self-employed and different things that's out there to help self-employed people and how to become self-employed.

Dahlia shared that friends and family are important for her emotional well-being.

Dahlia's response:

This is going to sound really terrible, but I will go off the radar for two weeks; I am not emotionally hungry for socialization. Wow, I really need to get out and see someone this weekend. But what my friends know that about me and they speak, "Hey Dahlia, are you in your hermit hole? Do you want to go maybe get some lunch? I can take you to Chick-Fil-A." I will say, "Yeah, let's do that. You are not wrong. I need to put on some clothes today." [LAUGH]

Steve shared that his social circle centers around church, family, and his professional work:

I spend a lot of time um, socializing with my NFB friends and family. That's been very important. I probably know my staff that I supervise entirely too well. Any of them are people that I worked with side by side before moving to that level. I still interact with, many of the TVIs and that I've worked with over the years.

There are people that will come here for a meeting, and the whole purpose is to go to dinner with me and others that are close. We continue that social circle.

Summer shared that she has great relationships with other people because she loves helping other people. Also, Carolina girl shared that her relationships with other people are great and that she is very satisfied with those relationships:

I have a great relationship with people that I lead; sometimes it's to a fault because been friends can get in the way of that. But I have a great friendship with people that I do not work with from church, community, neighborhood; I am very, extremely satisfied with the relationships.

Daytime stated in his interview that we need other people to lift us up:

If I haven't heard from a friend in a while, I may call and say hello. I may call and ask them something, but I don't have a network of people, but, you know, provide support. I mean that's not what they are. But I guess we all lift each other up as people who live in the world. We all have friends and networks that we rely on to be happy, have an opportunity to socialize, and enjoy things together.

The subtheme of educating the community about Blindness and VI was common on all the participants interviews. People who are blind or VI like to educate others about their disability. According to Joseph (2010) when you educate people about visual disabilities, they tend to adjust their reactions towards VI. Phoenix Jackson wants people to know that he is like everyone else and can do the same things that sighted people do:

The thing that stands out the most to me is getting people to understand that I'm pretty much other than not being able to see have a lot of the same interests that they do. And, um, I'm able to do a lot of the same things that they can do. I mean, I have to modify it in certain ways, but I can still cook, I can still do laundry. Um, you know, I could still do, you know, computer work with the assistance of, um, you know, speech software or things of that nature.

Dahlia loves hiking. She shared in our interview a conversation with a sighted person in a hiking trail:

We were hiking the other day, uhm, the girl who we were hiking with said, "Oh, you should try this other trail, it's flat and it will be not so many roots to avoid, and I think you can really like this place," and I said, "Oh, where is it?" And she said, "It is above the Pick exit." I said, "That will be nice, but I have to figure out

how to get there.” And it never crossed her mind! So, she said next time, if you need to go someplace, you should go there. I need to figure out how to get there. Daytime shared in his interview that people who are blind get the information through four senses instead of five:

So, people don't understand the difference between competence and blindness as being just a barrier to information. This is one obstacle to obtaining information because you're only relying on your other four senses to get the information you're relying on touch, taste, hearing, and smell, but not sight. People get information through their five senses, because you're blind you only have four senses to get that information. But that doesn't mean that a blind adult is not reasonable enough to act responsibly with the information they have. It's just that they're trying to ask so they can get that information in a different way because there may be a sign that says Concord C at some point. But if that sign doesn't talk, then the blind person is not going to know which direction to travel.

Additionally, Phoenix Jackson shared how he babysits his grandchildren. My field notes indicate that he was very happy talking about his grandchildren:

I love babysitting the grandkids. You know, I babysit, and people wonder like, “Okay, you are blind? How do you keep up with the kids?” You see, I keep kids the same way everybody else does. When we're inside and make sure the doors are locked that they can't get to it. You put all the safety plugs into the electrical sockets; you put the little locks on the cabinets where they can't get to poisons. It is the exact same thing that you know you would do. Um, if they're really little

and they're like infants, you put their little booty shoes on with the little jingle bells on the shoes, and you always know where they are.

Daytime, as my field notes indicate, is frustrated with people that like to treat him as a seven-year-old:

For example, well, let's put it in a social setting. So, let's say I'm having a beer over at a friend's house or something, and I go to through my bottle away, and they grab it from me and toss it. They'll tell me I got it, and they take it and throw it in the trashcan, whatever that is. While that's helpful at that moment, I still don't know where the trashcan is, every so for the rest of the night. I don't know where the trashcan is, so it's actually better if they would just show me where the trashcan is so that I can toss it, and you know that way, if there's something else, I need to throw away, I can do that. And lastly, if I'm in an airport, for example, uh, people think that I need someone with me just every step of the way because they see me as being no different than a minor child, a seven-year-old, for example, trying to go somewhere I have the maturity of an adult. But if I go to the airport restaurant and grab something, I may want to throw away my trash when I'm finished eating. So, if you're seven years old, you don't know to throw your trash away and wash your hands. When you finish eating, you won't get up and start playing or looking around or whatever seven-year-old. So, some people come up to me, and they'll offer to take my trash. I want to know where the trashcan is.

All the participants expressed the need for the community to be educated about blindness.

Summer stated an important message in her interview that you can educate and help

others just by talking to people. Also, you can educate and make a difference even when you are silent:

I just love talking to people and getting to know people and for people to get to know me for who I am. And, once they get to know me, they always say, oh, you're a totally different person for who we would think just being around you because a lot of people look at visually impaired and blind, we can't do nothing. And so, a lot of always come back and say, I'm just so glad that I got to know you and you really made a difference in my life. Like a lot of the ladies at the gym. They always are telling my trainer that I motivate them and they watching me to see how I'm doing. So, they be like, well, I can do it. And they know my name. Well, Summer can do it, then I can do it. So, she always, you know, telling me what they say. And a lot of them now, they've gotten comfortable. So, they open up now, they'll just tell me their selves. And that makes me feel good to know that I'm helping you know someone else. Even when you're just silent. You're helping someone.

Phoenix Jackson shared in his interview how important it is for people who are blind or VI to make themselves more accessible and available:

We truly need to make ourselves more accessible to the public that they can see that we are productive members of society or the upcoming youth can be productive. Members of society like that. These doors that we open up should not to be the last ones to walk through. We need to have an evolution of visually impaired people in other prominent positions. And to show that they can do the jobs that used to be unheard of, you can do it. I mean, now you have, blind

engineers or computer programmers and do different things like that but I feel like we need to be more visible in that so people need to see that we do exist and just talk to people on the basic level that they understand. Yes, you have a system where you can match your own clothes, you know? Yes. You can cook a meal. Yes, you do vacuum and wash the dishes or unload the dishwasher. We do everyday things just like everyone else. And we also can-do extraordinary things like everyone else.

Steve shared in his interview that people need to know that it is OK for them to offer assistance and have it declined:

I remember being propelled across the street in Colombia one time, by a sighted person who was just trying to do a good deed and just startled me. She caught me off guard, and I really didn't want to across the street. I think teaching people that it's OK to for them to offer assistance and have it declined; I think that's very important.

The social skills component is one of the subthemes that may influence how the people who are blind or VI are accepted in the society or work environment. Daytime explained that people who are blind or VI may not understand facial expression or body language. Guererro (2017) supported that all the social skills for sighted children are learned through visual observations of the environment and other people. Daytime shared that his brother wanted him to look “normal”:

My brother did his best to teach me. He let me feel things. I do not know why he thought that was important to teach me. He was three years younger than me; he wanted me to teach how to do things and how to communicate visually. Even I

couldn't see the replay to me, I can communicate to somebody by (smiling, nodding, and shrug shoulders). And people can see what I'm doing even I do not see what they are doing back. Because he always wanted me to look "normal."

But he thought that was something wrong looking blind.

Guerrero (2017), reported that the social component is an area of concern because social interactions are visually rich encounters that many times students who are blind or VI miss. Carolina Girl, as my field notes indicate was very patient talking about the stereotypic behaviors or blindisms:

Let me tell you, my parents would not let me get away with any of that craziness. No bobbing, no rocking, no shaking, no staring at the ceiling, staring at your fingers that none of that stuff. Because how are you going to know? Like, people learn through social interaction. So, with our blind kids don't know that it's not acceptable to rock in, poke your eyes, or anything like that. Because you are already kind of ostracize sometimes, you're already looked down upon because of your blindisms. And then you add blindisms on top of that. A great way to isolate yourself.

Daytime shared that he ran twice for office and how hard it is for a person who is blind to be a politician:

One barrier that I couldn't figure out to overcome was that all the politicians need to be able to run up to people and shake their hands or pat them on the back and say hello, kiss babies and stuff like that. And I could not find people. They would try to get out of my way if they saw me coming towards and say hello. They'll be

afraid that I was going to run into them. And they'll be afraid of the idea of interacting with a blind person. That causes simple apprehension.

These findings supported the research and the literature of inappropriate reactions toward blindness and VI (Joseph, 2010).

Advocating for Other Individuals who are Blind or VI

All the participants shared that they advocate for students and adults who are blind or VI and like to advocate for individuals who are blind and VI. Carolina Girl shared in our interview how she advocates and helps parents of the children who are blind or VI. She explained things to parent form the perspective of an adults who is blind herself:

So, when I'm talking to parents, it is huge, because you're already standing out, not necessarily in a good way. You're already standing out because you're blind, you use cane, use a dog, and are already seeing the people will notice you. So why in the world would you allow your child continue to poke their eyes or, you know, stare into space instead of looking at you or looking in the direction of you and that is so huge for me. So, I tell parents, I know that you care enough about these kids, and you want to go visit them in their apartment or in their house, or whatever it is one day. So, you need to curb those blidisms very, very early. So, as a parent you don't want to embarrass him/her in front of others. Now, if you're by yourself, it doesn't matter. But if you're, you know, their inner group, or small group, and you make up a codeword, you get from codebook, instead, they that focuses them on, oh, I'm doing something I'm not supposed to do. So, you may say pizza, or you may say Bonanza, or whatever it is. And then, that says to them,

oops, I'm doing one of those things that I'm not supposed to do. But the thing is, you got to have a parent that's willing to do it and do it consistently.

Summer shared on her interview that her sister lost her vision due to an accident and Summer stated that: “She's also blind now, and she was not blind as a child. Hers came from a car accident. And, um, so, I'm teaching her how to do a lot of stuff.”

Additionally, Phoenix Jackson shared that he promotes fitness to students who are blind or VI: “That's one thing that I really try to also promote amongst our kids. It's like you don't have to be a bodybuilder, but you don't need to sit in front of the computer screen for 12 hours a day, either.” Next, I will address the theme of transportation, one of the biggest barriers in the life of adults who are blind.

Transportation

Transportation is the biggest barrier for adults who are blind or VI. Transportation includes transportation for work, medical appointments, leisure, and other daily activities. Summer shared that she is self- employed and her husband works third shift:

As far as transportation goes, I have an employee that work for me. So, she drives to work and back home for me. My husband, he takes me to most things that I have to go to. And then I also have, you know, friends that are around here, they help me out when I need help, like with certain things, if they're available, or I catch Uber if none of them can't. My husband, he works third shift. So, he sleeps during the day a lot of times. And most of my friends, they work during the day. So sometimes I will have to catch Uber to go to the doctor's appointment. Or, if I need to go to meetings.

Daytime claimed that blindness is not a barrier to transportation. It is the issue of the public transportation and public resources:

So, if you live in a major U.S city, you might have a city bus or subway or something, so granted, if you live in a more rural part of the country, you will not have public transportation. But it is not blindness that creates that barrier. It is a lack of willingness to public resources into transportation for the public. But that's irrelevant in terms of being sighted or blind. If there's no city bus, then no one has a city bus. The bus is not just for blind people. Again, I reiterate that if you're blind and want to get somewhere bad enough, you will get there.

Dahlia shared her experience with public transportation. One interesting fact that Dahlia stated was that when public transportation is available and reliable to all people, that includes people who are blind or VI:

The best public transportation that I've ever had access to was in Clemson University. I got supper spoiled there. Their busses run on schedule, they are free and run a fifteen-minute loop. That made my life so easy. Where I live now the busses run in a pretty good schedule, I am not complaining, but not like Clemson University!

Carolina Girl bought her own car to solve the problem of the transportation:

I know other blind folks that have bought their own cars. But, you know, I've kind of been on that teeter-totter with that and decided I'm going to do it. And, you know, I made up my mind, and it's been so easy, much easier to say, "Hey, can you drive my vehicle?" Then "Hey, can I, four of us or three of us ride ride with you in your vehicle?" So, I mean, all you're really paying is now is their time. It's

not the maintenance on their vehicle. It's not the gas in their vehicle. You're paying them for their time.

Daytime shared on his interview that he can't legally drive yet. He is looking forward to the self-driving cars. Daytime shared:

I have a friend who owns the transportation business where I live. I may use different means to get around, but at the same time, my wife that I only own one car, drives the car that we own, but I don't need to own a second car with additional insurance and gas and car payment. So, I use that for a couple of \$100, perhaps for any transportation needs that I may have. If you're a young, blind person, let's say like when I was 18 years old, that was on SSI, I and did not have the means that I have now. I didn't have the means to get just anywhere I wanted to go, um, with cash on hand. But if I wanted to get somewhere bad enough, I found a way to get there. So, you know, I might have used the transportation excuse if I didn't want to go to some kind of a meeting or something like that. If somebody invited me to a network marketing meeting, I might use a transportation excuse. Even if you have to trade it if you don't have the money to hire somebody even before existed, there might be someone you know, uh, a trade-off that you would do for somebody else that they need help with. So, I mean, that's why. Again, I reiterate that if you're blind and want to get somewhere bad enough, you will get there.

Dahlia shared in our interview that the location was very important for her when she decided to buy a house. She worked with a real estate agent and stressed that location and city bus transportation was very important for her.

Dahlia's story as homeowner:

When the time come to buy a house and get a job it's no accident that I live right here. It took six months to find this house. I drove the real estate agent bonkers. She will say "You said you wanted two bathrooms." And I will respond, "I would like that, but I don't care. It's location, location, location. Right?" It is what I wanted in a middle of two city intersections of three major bus lines that are nearby. I could walk to the Family Dollar; I can walk to the park. Back when I worked at the Commission for the Blind, I could walk to work. I've got friends who are less independent, not because they don't have the self-determination, not because they don't want to be but surely based on where they live. You live at the end of dirt road, you become very reliant on others.

Long-term investment should include transportation access in underserved areas, as well as sidewalks that connect people to services, transportation hubs and their destinations (Rosenblum et al., 2020). My field notes confirmed that I arrived early for the appointment with Dahlia and I drove in Dahlia's neighborhood. Dahlia lives in a very convenient place, very close to public transportation and walking distance form a shopping center and a city park. Guerrero (2017) identified transportation as one of the barriers to employment of people who are blind or VI. Next, I discuss the theme of the attitudes and reactions of people towards blindness.

Attitudes Towards Blindness

People have unappropriated reactions towards blindness and VI. Research (Litfshitz et al., 2007; Joseph, 2010; Hong & Erin, 2017) suggested that people's

reactions to blindness can be associated with not understanding blindness as a visual disability. Joseph (2010) stated in her study that people's reactions towards blindness and VI are positive and negative, but mostly people are uncomfortable around people with disabilities. Daytime as my field notes indicate, walked independently in the restaurant using his white cane. But he shared that walking by himself in the restaurant made people uncomfortable:

When I first walked to the restaurant people were a little scared, they thought does he know where he is? What is he going to do, ask for directions, and I said that I am waiting for my friend because you were parking the car, and you came in. When first you see a blind person, most people are just a little bit apprehensive because they do not know what to do.

There is a lack of education about blindness and VI (Joseph, 2010). Some people who are blind like to educate others about their disability. Joseph (2010) supported the idea of education and further stated that when you educate people about visual disabilities, they tend to adjust their reactions to VI. Phoenix Jackson shared in his interview that how important is to share with community about blindness and VI:

I was pretty involved in different things with my church and volunteering with the Spartanburg Lions Club. I would go and speak to different Lions Clubs, around in Spartanburg. Just for the awareness to. Also, I spoke with the Girl Scouts and the Boy Scouts. And I try to be an ambassador for people with disabilities, from the visually impaired and blind aspect to give people an idea that for the most part, most people really never come in contact with a Blind or visually impaired person. And if they have, it's always been, you know, and no, no offense. It's

always been like some 85-year-old or 90-year-old or grandparents they are not really active for, you know, doing things in the in the community on that. So, when they hear like, oh, you work and coach, it's like, “wow, I didn't know these things existed.” So, it is kind of opens the eyes of even the young people. Because if you can teach them these things when they're young in the public, then they're not going to look at you know, someone who's visually impaired or blind like there's some aliens.

Dahlia’s interview supported the idea of education but added that she gets a different reaction from people:

I think when you get to talking to people and you put them at ease a little bit, people normally are more likely to me like anybody else. But it 2020, and people still like to touch me, pray over me, and tell me how amazing I am because I got out of bed this morning.

Additionally, Dahlia has an invisible visual disability. Dahlia’s blindness is not easily recognized by a person who is sighted. Dahlia shared on her interview that her visual disability is a double sword and she let people know about it.

I have been accused being rude, I have been accused been drunk because I did not see what is in front of me and crashed into something. And, I learned it, later in life, much later in life in my late teenage years, it is always better for people to know. I rather let you know that not know. It is hard to hide it. It’s exhausting to hide it. So just go ahead and say it!

Carolina Girl talked in her interview about the stereotypic behaviors or blindisms that some of children who are blind or VI exhibit in social settings and shared some of the

strategies to help teachers, parents, and students. My field notes indicated that Carolina Girl is very enthusiastic when she talked about the codewords:

So, our blind kids don't know that it's not acceptable to rock in, poke your eyes, or anything like that. Because you are already kind of ostracized sometimes, you're already looked down upon because of your blindness. And then you add blindisms on top of that. A great way to isolate yourself. So, what I have started doing with some of the parents is that that's good training for them. So, you don't want to embarrass him in front of others. Now, if you're by yourself, it doesn't matter. But if you're, you know, their inner group, or small group, and you make up a codeword, you get from Codebook, instead, they that focuses them on, oh, I'm doing something I'm not supposed to do. So, you may say pizza, or you may say Bonanza, or whatever it is. And then, that says to them, oops, I'm doing one of those things that I'm not supposed to do. But the thing is, you got to have a parent that's willing to do it and do it consistently.

Next, I address how participants are involved in the communities where they live or work.

Involvement in the Community

All the participants are involved in their communities where they live or work. Carolina Girl stated that she is involved in her church, neighborhood, and in the blind community. My field notes indicated that she is very excited when she talked about her church family and her involvement in the community where she lives. Summer has traveled around the state to speak in different events about blindness. Summer shared in

her interview that she is involved in a lot of fundraising for NFB in her community where she lives:

Sometime in the future when the pandemic slows down, we are trying to get more members, we will do a membership drive. We go to Columbia for different meetings, we trying to set to go to different schools or churches to speak so people so they know who we are and learn more about blind people. And, we go to Washington a couple of times a year to the Capitol Hill to meet with different legislators.

Daytime shared that his involvement in the community has changed through the years:

I don't do as many community things that I did at one time. But I'm still a member of a local church and I'm still a member of the NFB. I get involved from time to time in community affairs here at the community that I live in. If there's an association board meeting, for example, I may go. If there's something I want them to know about, I get involved in issues like that. I've always been very involved in what's going on around me. In high school, I ran for office, student council and was in school play and then the school choir and then all those things and continue to do so throughout my adult life until probably just very recently have stopped.

Dahlia shared her experience what it is to live as a person who is blind and helping people who are blind through work: "I used to be very involved in the blind community, not so much anymore. I know I had to take two giant steps back just because I was like doing it all day for work and then living full time as a blind person. Just gets too much."

Summer shared that she has great with relationships with other people because she loves helping other people. Also, Carolina girl shared that her relationships with other people are great and she is very satisfied with those relationships:

I have a great relationship with people that I lead; sometimes it's to a fault because been friends can get in the way of that. But I have a great friendship with people that I do not work with from church, community, neighborhood; I am very, extremely satisfied with the relationships.

Phoenix Jackson emphasized that the relationships with other people especially people he works with are built in trust and integrity:

I'm more or less observing people around me to see how they interact with other people before I opened myself up to them. Because if you're good and you are kind to other people around you and then you've already shown me then you're probably going to be a good and kind person to me. So, the relationships that I've built with the people that I work with is built on trust and integrity. I think they also know that I am dependable. I feel like that they can depend on me, you know, and that that's one thing I think all people who are visually impaired strive to have someone to say is that they are dependable. I'm always striving to make my relationships with people better. You know, I'm always looking to see how can I be better, how can I be more, whether it's me being more patient, whether me listening more whether I mean educating myself on things that are interesting to other people around me that I don't know about, because one thing, if you can get people talking about things that they're interested in and you show an interest and that you may not be an expert in it, and you may not know that much about it, but

even if you just have a little bit of a knowledge about it, it can open up a lot of doors to make people more comfortable with you or you with them. I'm just always constantly trying to be a better coworker or a better friend. Um, you know, to the people that I work with or that I even socialize with.

Daytime stated in his interview that it is important to him to stay in touch with friends because we lift other people up:

If I haven't heard from a friend in a while, I may call and say hello. I may call and ask them something, but I don't have a network of people, but, you know, provide support. I mean that's not what they are. But I guess we all lift each other up as people who live in the world. We all have friends and networks that we rely on to be happy, have an opportunity to socialize, and enjoy things together.

All the participants shared that they are very involved in the communities where they live or work. Next, I discuss the theme of the services that communities where the participants live or work offers to them.

Community Services for People who are Blind and VI

All the participants responded to the question, “What does your community offers to people who are blind or VI?” and shared their life experiences about how they access services provided by the community. Daytime shared that transportation is one of the biggest issues that people who are blind face:

So, transportation comes to mind. Well, there are federal and state agencies that have local offices, uh, that provide various, whether it be financial assistance or rehabilitation at the local level. But they're usually organized at the federal level

and the same level, and we're just visiting a satellite office to access those types of services. Some localities have transportation that they provide to the general public, or perhaps, medical appointments if you have some kind of disability. Most cities have a transportation service for people with disabilities. That's more of door-to-door type service. And, so if you need to go, you are not close enough to where a public bus stop would be, then the Disability Transportation Service would get you there. So, that's in some communities. People are fortunate enough to have access to that, and it's available where I live as well. So, I usually don't use that because I find it easier for me not to have to do any ride sharing, but that again goes back to what you're able to afford.

Also, Daytime specified that the services provided by the different civic organizations depend on where you live:

But as far as blindness services specifically, it probably just depends on where you live. Whether private organizations for government programs that may exist do different things for blind people. So, there may be something in MB, would it be you know, Lions Club chapter or something like that. In addition to the Commission for the Blind local office and SCsDB. They had a field office, and still, I don't know if it's still there or not, but that would be the extent of my knowledge about services that are explicitly provided for blind people.

People who are blind and VI are part of the general population and the community.

Daytime shared that their QOL depends on the services that are offered specifically for them the community where they live and work:

But as far as overall public services, blind people take advantage of those just like everybody else. Trash services, the DMV, whatever other kind of things you can think of. Blind people participate in those things as well, so their quality of life is no worse than somebody else's. It is just based on the existence of blindness-specific services for something people might say. For example, well, if there are no services specifically here for blind people in the area, your quality of life is worse. But that really wouldn't be true, because the blind person also has access to the other services that are offered to everybody else is part of the general population.

Carolina Girl lives in an area where public transportation is not offer. She shared what her community offers:

They offer Uber and Lyft, public transportation if you are in the right area [LAUGH]. Not in my area. I access Uber, Lyft and as for shopping Instant card. I love it, even Instant card or UberEATS, even the eating apps, you know, the take-out apps, grocery apps, it is so, it has been so much help.

All the participants addressed how the federal and state agencies that support adults who are blind and VI. Such agencies, Commissions for the Blind, SCsDB, and NFB, play an essential role in students' education and employment of adults who are blind and VI. One of the participants, Carolina Girl, shared her experience with Commission for the Blind:

I am a product of the Commission for the Blind. But you still had to advocate. They almost did not pay for me to get my Master's. Degree. I had to write a dissertation about why they should pay for my Master's degree. Because a BS in

psychology is not going to get you a high-paying job. [LAUGH] Not that I am in a high-paying job now. But it will be a lot harder to find employment. I have done something with that. Their money has been well spent on me. I feel like now they do not appreciate, they do not acknowledge the informed choice, consumer informed choice, I think that there are no high expectations for blind people, there are any blind staff as role models. We have centers close; they are not allowing people to go outside of SC to get training, that is under informed consumer choice. They can do so much more.

Daytime shared that he worked for the Commission for the Blind:

I worked at the Commission for the Blind; I was a rehabilitation counselor. Luckily, the agency at that time believed that I knew something about blindness, and I didn't have formal education in that field. They thought I could be a good role model. And I had worked with VR counselors in my own career. I had participated in the writing of my, uh, individualized plan of employment, um, and do things as a consumer. So, they thought, well, maybe he would be a good counselor as well. But that wasn't really what I had set out to do in life. That was an honorable profession. And I have many friends who are in that field. It's a great field to be in, but I kind of thought I was more interested in law and politics. They have a lot of very caring people, a lot of people who worked very hard to improve the quality of life of blind people. I was able to go to college and law school with financial assistance, so that was very helpful. And I also met people who are employed there who are still friends of mine to this day, who are great

professionals. Some of them are retired now, and they cared very much about their jobs and the work that they did; they're very proud of what they did.

Summer shared her experiences as client and as a parent of a student with VI:

I remember a lot as a child. Um, my mom didn't know a lot, but my vision teacher from public school, she used to try to get me a lot of assistance through the Commission for the Blind. And it will always be different. Situations came up where things will never actually go through for whatever different reasons, I finally started getting service, um, from the commission, I think when I was in, like, the sixth grade, but it was so brief, and it was not what I needed to stay in public school system. And that's how I ended up at the SCSDB, because I kept just getting behind every year because I was losing my sight every year. My sight was getting worse. And by the time I got to come to the SCSDB, I was basically writing with a big, large magic marker. I didn't see my work, and I didn't have no services from the Commission for the Blind to even teach me Braille or anything at the time. I got older and got out on my own and reached out to the commission for assistance, it always been they're going to get back with you or it always some type of reasons why you couldn't get serviced or your counselor left and your paperwork got shelter to the back or can't find the paperwork.

Summer shared that as parent she is still experiencing issues with the Commission for the Blind:

And now, as a parent, I'm still experiencing the same issues. My son has had some Commission for the Blind counselors that really kept in touch and help him out with things that he needed for school. But for the most part, they change

employees so often. And it's always a reason why something didn't get done; very overwhelming and stressful. And hopefully, in the future, they're going to get better with that.

The Commission for the Blind is a very important tool because like the SCSDB enables the government to provide specialized training or services to blind people who might not be able to get that training in other settings. Daytime emphasized that:

Because of the training that we need while I do access the community's services the way other people do, when you're growing up, there are some other things you need. Like I mentioned, the Braille instruction or cane instruction. Those kinds of things were very important, and I had to get those through people who knew how to teach me those things. As the commission for the blind helped with that, though, like every other program, there were times when I was frustrated about what the commission did or didn't do. But I always let them know about it. I'm very glad to see what they've done in recent years in terms of outsourcing their training so that organizations like the NFB through Successful Transitions can provide mentoring, and other types of experiences to blind people of different stages of life, particularly of young people who need specialized training as they're growing up.

Dahlia shared her experiences as a consumer and being served by Commission for the Blind and of working for them:

I went up through children's services, summer teen programs, I had more good counselors than bad counselors. I got decent services coming up, only when I worked there, and kind of look back, I realized that I did not get everything that I

was entitled too. But at the end of the day, I made it. I am fine. I went to work for them because was an opportunity was a job and was a salary that at the time seemed more money than I have seen before in my entire life. I needed a job, and I needed to start somewhere. And on the other side, I said: “Cool, I need to help people that I like to help anyway, cool.” Back in the 90s, the Commission was in a better place that is today, it was better.

Participants provided information of their involvement in the organizations for the blind such as NFB as well supporting each other in the communities where they live. Three of the participants are presidents of the NFB chapters in their communities. One of the participants shared on her interview that she would like to be in NFB National Board. Summer is the president of NFB chapter and the blind merchandise of the community where she resides. Summer spoke how they support each other in her NFB chapter:

We do a lot to supporting each other there. Sometimes if we have, like my employee, if she's available, she can help some of the other members who are in my chapter. We actually go out and do things, like talking to people and meet with our legislators to get to know them and for them to get to know us. But when we have different situations come available, they will know who we are, and we will know who they are. So, we do a lot of stuff out in the community.

As Daytime shared in his interview, the Commission for the Blind and SCSDB are important tools that enables the government to provide specialized training or services to blind people who might not be able to get that training in other settings. Next, I discuss some of the findings that are related to the theme of voting.

Voting

One of the themes that all the participants shared and discussed was their voting experiences. All the participant shared that voting is very important and all of them have noted in the last presidential election.

Daytime shared his first voting experience:

The first time I've ever voted, I went into a voting booth with my mother when I was 19, and, I voted in a presidential election in South Carolina. An initiative, basically, uh, an initiative, that the NFB of South Carolina was very proud of became statewide law. Required voting pressings to allow a blind person to select, um, someone of their choice to go through a booth and help a person's vote. And that was very helpful.

Also, Daytime shared an important legislation piece, Help America Vote Act that made the accessible voting technology in 2006. My field notes revealed that he got very excited when he talked about using for the first-time accessible voting machines:

After the Help America Vote Act was passed, uh, shortly after the election in 2000, I think it might have been passed in 2002, the implementing regulations were required that accessible voting technology be available by 2006. By that time, I had voted in every election, and but I always had someone help my vote in 2006, my son was six years old, and, he and I walked into the voting booth together, but not so that he can help me. Uh, but so that I could vote by myself because I was able to use the accessible voting technology that was finally

available. I was able to do it independently because the NFB convinced Congress to include in the provision of the Help America Vote Act a requirement that, voting technology also be accessible by non-visual means or through non-visual means.

Daytime, as my field notes indicate got emotional when he talked about taking his son to the voting booth:

Just like other children go into the voting booth with their parents. My six-year-old came into the booth of me because I wanted to teach him how important it is to vote. It wasn't because I was blind. It was the father and son thing. We always took him when we went to vote. And to this day, he's very interested in politics. He saw me voting there. I was thirty-seven for the first time voting independently, and that was special.

Summer stated in her interview that was very “voiceful” about voting, if you do not vote you have no right to complain:

I encourage everybody to vote. I'm very voiceful about voting and having your rights. I've had several friends that you know don't vote, and I've talked a lot of them into voting, you know, in the last 10 years or so, like one of my friends, she's never voted. She's older than me. She's never voted before. And I finally encouraged her to vote because I make, I tell them. Well, if you don't vote, you have no right to complain. Correct?

Daytime is so proud that he ran for offices and that his name was on the ballot:

When I ran for offices, it was special to go into the voting booth and vote and see your name on the ballot, it's was like, it's kind of like hearing your own song on

the radio. If you're a singer and you hear your song, so voting and you read down the list of candidates, and you see you know, you see your own name is kind of funny, So I saw Daytime. And, of course, I voted for that guy,it was really fulfilling and uplifting. By the time I ran for office, I was able to vote independently, so I was actually able to see my name on the ballot scroll through.

But Daytime noted that absentee ballots for people who are blind “need more work”:

So voting is very important. I voted the last couple of elections independently, this time however, I voted absentee, which South Carolina still needs to do some work on absentee ballots for blind people. Anyway, I've always been able to vote one way or another, usually independently,

Rosenblum et al. (2020), indicated in their study that accessible voting machines must be available at all polling locations, and workers must be trained on their use so they can provide instruction to voters as needed.

Dahlia’s experience with the last voting indicated that training is needed for the volunteers at the polling locations. Dahlia walked with a friend at the vote precinct and asked the person for an accessible machine when she entered:

“I am going to need an accessible machine; can you go ahead and pull that together. And the person responded: “We do not have one” My friend said, “Oh, I can go and help you.” And I said, she doesn’t know what she is talking about, let’s keep going. When we got to the front of the line and I asked the person who was checking my ID. “Hey, I need an accessible machine. Can you have somebody get that?” And she said: “I do not think we have one.” And I said: “You do, Go find it.” And sure, enough they did. They found it. I think I made

them uncomfortable or I made think out of the norm? When I told them, I need an accessible machine I do not need head phones, I had my own headphones, they did not process any of that. So, they got up and got this old, blocky, school headphones that had these covers over it, them and covers are falling off, this guy is struggling to put the covers on and my friend said, she was still with me, he finally got the covers on the headphones. He looks at the headphones, and he looked at me, he looked at the headphones and he looked at me and he started to reach up to put the headphones on my head and she snatched them of his hands [LAUGH] before he can do it. [LAUGH] But at the end of the day I got to vote using the accessible machine. People where just were stepping away this time, but other times, I can just get in get out, you know no big deal. If that's the worst story I need to tell you, I am doing very good. [LAUGH].

Additionally, remote voting options must be accessible, secure, and widely available (Rosenblum et al., 2020).

Equality

Equality was one of the questions that I was very interested because the participants are from different age groups, race, and ethnicity. All the participants responded to the question, "How are you treated in terms of equality? The responses of the participants are cited below.

Carolina Girl:

It depends on the day and it depends on the time. I would say that I have had been rejected because I have a dog in Lyft or Uber, of course, reported, Uhm, I have

been, it has been a while, but I had to leave the store and the restaurant because of the dog, both. People are not educated.

Daytime:

I would say that my rights have been infringed upon very often throughout my life. Um, but I don't want to be too petty about it. Still, I would say every time an airline has an agent walk with me through an airport; whether I want them to or not, they're mistreating me when the people, when I walk through the metal detector at the airport, they about have a fit when I reached by to feel where the walls of the scanner are, so I could walk through it. They'll say something like, "Just go straight through," And so we're back now to the concept of how competent a blind person is, so I know just to go straight through. I understand how the technology works, but I've got to know where it is. I've got to know what the machine is. And what they do is they hold their hand out with their little gloves hand, and they want me to hold their hand so they can pull me through the metal detector. I don't want to hold their hand to walk through it. If you let me tap the walls with my cane and then back, I will then walk through it without touching the walls. I know that I can't tap the wall while I'm walking through it, but I just want to find it, just like when you're walking through you first, look at it, then you go through it. I'm looking at things by touch, so I first want to find it, and then I will go through it correctly. So, in that way, I have been mistreated.

Phoenix Jackson shared that he has been mistreated more as person who is blind than as a black man. He said that one of the reason people mistreated him was because they do not understand blindness or VI.

Phoenix Jackson:

Honestly, I've probably have been mistreated more as a visually impaired person than as a black person. And a lot of times I think that is because people don't understand visual impairments, I think they assume that and no disrespect, assume that number one you are fragile and number two that you're not very smart. For some reasons, people just assume if you're blind that you also have a mental disability as well. So, I've probably had more discrimination in that particular aspect of being blind than being black.

Summer shared an experience where she was not hired because she was blind:

I was put in a situation where they actually came out and made a comment that they didn't think it would work out because I was blind at one company. And when I went back and started talking to my Commission for the Blind counselor, she told me to call back to them and ask them to put that in writing. And when I did that, of course, they didn't want to do it. And that's when I start getting more involved in learning about American Disability Act Laws and rights for not just disable, but also for females, in those type of situations.

In summary, the eight themes that emerged through the interviews for the Social Participation factor and its domains are (1) Support Systems, (2) Asking for Help, (3) Participants' Community, (4) Advocating for Individuals who are blind or VI, (5) Transportation, (6) Attitudes towards Blindness, (7) Voting, and (8) Equality.

Next, I will discuss the themes and subthemes that data analysis revealed in the Well-Being factor.

4.3 The Well-Being Factor

The Well-Being factor includes: **Emotional Well-Being Domain** (Contentment, Self-Concept, and Freedom from Stress), **Physical Well-Being Domain** (Health Status, Activities of Daily Living, and Leisure), and **Material Well-Being Domain** (Financial Status, Employment, and Housing). (Schalock & Verdugo, 2012). The themes that emerged in the participants' data analysis are (1) Emotional Status, (2) Health and Fitness, (3) Accessibility of work and home, (4) Employment, and (5) The Material Well-Being.

Emotional Status

The emotional status was one of the themes that emerged from the participants' interviews in the emotional Well-Being domain. All the participants described their emotional well-being and shared personal lived experiences that were very meaningful. Dahlia: "Mhm, I think that I am good as I have ever been. [LOOKING AT THE GUIDE DOG] I have a good job, I have a good relationship, and a good home."

Carolina Girl's enthusiasm, as noted in my field notes is noticeable when she talks about her emotional well-being: "I am in a very good place. I am not saying that there are not times when I am feeling sorry for myself, but overall, my glass is always half full instead of half empty. Attitude and gratitude."

Phoenix Jackson emphasized in his interview that he has a good health and a good marriage: "I would have to say I am in a good spot in my life is as good as I can be. I mean, my health as well, my family are healthy. I have a very healthy and loving marriage."

Steve shared that as a young child, teenager and then a young man he had to find his place in his emotional wellness and as adult he makes sure that his emotional wellness stays safe:

As a young child, teenager and then a young man, I had to kind of find my place and my emotional wellness and what I had to do to ensure that my emotional wellness, um, stays safe. I went through depression because there were so many changes in my life that I just couldn't wrap my hands around, and I finally got some counseling, um, for that and got through that. And then I learned to identify the trigger signs and had to head them off, so I've never have gone there again. But it was it was the most difficult period in my life.

One of the subthemes on the emotional well-being was the participants acceptance of their Blindness. Daytime shared that his brother wanted to make Daytime as normal as he could. According to Daytime, if you look from a positive perspective, there is something positive to say about it OK but on the other side, “What is wrong looking blind? What is wrong with being a blind person?” Next, I discuss the theme of health and fitness.

Health and Fitness

The theme of health and fitness was addressed by all the participants. Phoenix Phoenix Jackson shared in his interview that one of the reasons that he stays in shape is to have a quality of life:

I always try to stay and especially recently with COVID-19. I know it's a tendency for people who are VI to be sedentary. Statistically, there's a high level of obesity, high level of diabetes, high level of heart problems within the visually

impaired community. Um, you know, because a lot of times they feel like they have to depend on someone to take them to the gym or someone to, um, you know, push them to exercise where I'm just the opposite. The ability to do sports in high school, I've always kind of maintain the mindset of, try to stay in some reasonable shape, even if it's just walking or something like that, just to make sure I have a quality of life. And that's one thing that I really try to also promote amongst our kids. It's like you don't have to be a bodybuilder, but you don't need to sit in front of the computer screen for 12 hours a day, either.

Summer's experience with physical and fitness is a success story. My field notes indicate that she is so proud that she has continue to exercise for the whole year:

Also, I have a personal trainer. She started off as a personal trainer for me, and now she's opened up a gym and I go to her gym at least five days a week. She has been phenomenal. She's very good about coming over and let me be able to touch her legs and arms so she can show me different routines. We have formed a "sisterhood" what we call it in our gym, and they treat me just like they treat everyone else there. You know, anything I need assistance with, they don't mind helping me. And we plan a girls' weekend trip to Tennessee in November, and I went with them on that trip and it was a great weekend and I zipped line for the first time. And, I encouraged them to go horseback riding. So, it worked out well.

Carolina Girl's treadmill was very close to where the interview took place. My field notes indicate that her treadmill is used a lot. Carolina Girl pointed to the treadmill and spoke with enthusiasm, "Do you see the treadmill over there? I walk on the treadmill until I have pain in my feet. No pain, no gain!" Carolina Girl shared that she has done few 5K

walks or jogs but that she would like to run the Copper River Bridge. She shared that she would like to invite more people who are blind or visually impaired to join her. Dahlia got excited when she talked about her Guide Dog:

I have been healthy my entire life, and this thing at my feet [POINTING AT HER GUIDE DOG] is going to make me walk more and be more active, and go on outings. I love to walk; I love to be out in nature. Researcher, “You give me the impression of a trail person.” Dahlia. “I do love that [LAUGH]. That’s how we grew up.”

Steve’s story is another example that teachers have an impact on the future of their students:

What had a detrimental effect on me was riding a stationary bike for 10 miles a day in PE class for two years. And, so I think that had a very negative impact on taking care of my body, physical education, and exercise. And so even now, if PT (Physical Therapy) is required, I’ll go in there, and I’ll say, “Okay, you can put anything in this room, but I’m not riding that stationary bike.” I still will not ride one.

One of the subthemes that emerged in the interviews was the relationships between vision and health and fitness. Dahlia shared on her interview that now when everyone is using apps, it takes longer for a person who is blind to access them. When I asked about their accessibility, Dahlia responded that the apps are accessible, but it takes longer:

Now in the age of apps, for example, the food diary apps, there are some accessible ones, it takes me twice as long, it takes an average person a little bit of time, double for me. The different times when a piece of new equipment, like the

peloton, is not accessible. I see that all these gadgets and gizmos are coming out; I certainly can do without them, I can be fine without them, but it will be nice to know that they are accessible. One morning I did a yoga class in undergrad. I wanted to do some salutation every morning. I wasted, I know, 45 minutes of my day just trying to find one where they were being descriptive enough for me to follow along. Just aggravating stuff like that. Not earthshattering but definitely aggravating.

Phoenix Jackson shared his experience using the fitness machines at his gym:

Now everything is a touch screen. When I'm on the treadmill or the elliptical, I usually like to take the little sticky tabs to put on what I want to go faster or slower or stop. And I just stick them on there, and I'll tell the gym people at Planet Fitness this. Look, I'm going to stick these on there, so you know what I'm doing. They will say, "Okay, whatever works for you." They're pretty accommodating. But sometimes I wish they would make more machines like that, they have some type of you know, kind of thing where you don't have to ask someone is which button is this or you know. Hey, I'm ready to stop.

Carolina Girl, as my filed notes shown, gets fired up when people make excuses about exercising and getting in shape. Carolina girl stated that, "There is no excuse [PAUSE]. You may not have a safe community; you can put something in your home, you can buy a piece of equipment to exercise." Dahlia expressed concerned about the limitation that the vision has to some of her physical activities:

I think been blind to a degree, it limits the options. I grew up biking. Loving been on a bicycle, and as soon that I realized that I am indeed breakable, riding a two

wheels bike is not something that I will feel comfortable doing. Same with hiking.

I need to be careful.

Additionally, Phoenix Jackson shared that he promotes fitness to students who are blind or VI: “That's one thing that I really try to also promote amongst our kids. It's like you don't have to be a bodybuilder, but you don't need to sit in front of the computer screen for 12 hours a day, either.” Additionally, all the participants have access to their health providers. Summers specified that a lot of the forms or important information at the doctors’ offices are on flat screens that are not accessible:

Um, I feel like some type of way, all the offices need to be more accessible, as far as having Braille or Auto Form, where people that cannot read Braille because we have, you know, a lot of blind people that cannot read Braille for different reasons. but even like the stores they go to. All of this flat screen, um, the touchscreens for you to pay with your debit card or your credit card. You having to rely on someone else to do it because it's a touch screen. The same thing at the doctor offices. So, I just feel like everything needs to be more accessible for the blind people and disabled people, in general. Especially at the doctor's office because a lot of information is so private. And it's just you just cannot share that with a nurse. And you know what I mean? It's like everything is so personal.

Rosenblum et al. (2020), suggested that medical providers should make written information accessible to individuals who are VI by providing electronic, braille, and large print options.

Accessibility of Work and Home

Steve shared on his interview that part of the accessibility for him is how he gets the information in electronic format or Braille:

My work environment is very acceptable. I will say that my supervisor values accessibility at an extremely level to the point that nothing is passed out in a meeting that is not either made available to me and I preferred electronic format or Braille. All offices are labeled with Braille and tactile. Uh, it's a very, very accessible place for me. And again, I think the fact that he values accessibility at that level, um, means that the managers that he supervises also values that same accessibility at that level. The work place is wonderful!

Carolina Girl shared that her work environment is very accessible to her and to others. My field notes indicate that her home is very accessible, too. Phoenix Jackson shared in his interview that the environment where he works is very accessible, but he shared a concern about the new technology and the importance of input from the people who use it.

We have very decent accessibility where I work. Um, because that's kind of the premise of what we should be here. But I will say this, I think sometimes with all the technology that comes out, we need to be a little bit more careful to make sure the technology we get is compatible with the technology we have. Because a lot of times, we have a lot of problems with the cohesiveness of trying to mesh multiple technologies together or even the ability of kids to officially use certain technologies. You know, um, I do have frustration with IT. Because I feel like you need to have the insight of someone who is using this technology. Before you

say, “Hey, that looks good, I think we can use that.” But you're not the one who is using it. And then you spend all this money, and then you have an \$8,000 piece of equipment in the closet because it's not really relevant to our population.

Summer described her work environment as “very accessible”:

I fill up vending machines and I put them away. I have everything at my location. I have everything organized in my storage building. The way is lined up in the machine, it's in my storage building lined up the same way. That way, when I go to work when I need to pull coca cola, I know exactly where they sit on the floor. If I need to pull a bag of plain chip, I can go and count my boxes down to I know I'm at the correct box and I keep everything very neatly and organized that way. If I, you know, have to go to work one day with someone that's not my employee, for instance, in the past where she was out sick on medical leave. I had to get one of the ladies from my church that's an elderly lady who wasn't able to really physically do the work. But she could drive me there. And so, she was just going to sit and watch me. But I had everything all nice where I could just go in there and pull them in the machine.

Summer values that she is self-employed. Next, I will discuss the employment theme and subthemes that were revealed through the data analysis.

Employment

Under the theme of the employment five subthemes emerged (a) working with children or individuals who are blind or VI, (b) transportation, (c) correlation between Braille literacy and employment, (d) support at the work place and (e) employers' attitudes towards blindness. All the participants have worked or work with children or

individuals who are blind or VI. As noted in my memos, Phoenix Jackson is full of joy when he talked about what he does for work:

I truly do love working, and I think the job that I have now working with kids who are where I used to be and trying to offer them some of the same advice that was given to me without being overboard. I think it's always a touchy situation where you don't want to overdo it and turn someone off that they do not hear you, but I try to find ways to encourage and foster that independence in the kids.

Additionally, Dahlia highlighted in her interview the correlation between Braille literacy and employment:

So, there is a huge correlation between Braille Literacy and Employment. One cannot read, one cannot write, so you are illiterate, and computer cannot read and write for you. You can try but is not. You do not learn spelling, you do not learn punctuation, and you do not learn formatting. The computer cannot do that for you.

Another subtheme in the employment was support at the work place. Phoenix Jackson spoke highly about one of the colleagues at SCsDB and the support she gave him when he started working there:

For someone who is not visually impaired, she probably taught me more about being visually impaired than anyone that I can really mention. You know, just being comfortable with me in the workplace. She taught me how to be comfortable with myself in the workplace. Everyone needs a Miss C in their life!

Transportation to work continues to be one of the biggest barriers in the employment.

Guerrero (2017), found in her study that transportation was one of the barriers to

employment of people who are blind or VI. Phoenix Jackson shared on his interview that it is okay to say “No” for a ride to a person who is blind:

I have several coworkers sometimes, you know, they’ll give me a ride home, and a lot of times they’ll ask me, “Hey, do you need a ride home today?” Because I don’t make it a habit of just using them all the time. I expect you to give me a ride or something like that, and I give them the option that they can say, No. If I ask them a question or favor or something that they don’t have to feel guilty by saying no, just because I’m blind, it’s okay. You can say no to me, just like you would say no to anyone else. If you’re not able to do it, I don’t want you to make a special effort. If it’s not convenient to you, you know, I only do it if you’re able to do it and you want to do it. And I think by being upfront and honest in that note and allowing people to be honest, it makes it more comfortable with me. So, I think they’re more willing to just offer, you know, just offer their help.

Another subtheme under employment was the employers’ attitude towards the population with blindness. Daytime emphasized that the employers’ attitude towards blindness limits the opportunities for individuals who are blind or VI:

Sadly, if you come out of school there is not a lot of career opportunities for you as a blind person. The employers will think even with all of us been equal, the blind person may not do as much as the sighted person. So, the sighted person gets the job. If I walked to the hostess stand at this restaurant and applied for a job as a server, you can tell that I have the personality for that, I can talk, I have no problem speaking but they will not give me a chance because they will think: how is he going to find the tables? How is going to know food to bring to the tables?

Or to take a to go box? So, the employment opportunities for blind people are more limited not because they want to but there is a bigger barrier to the person's potential.

Summer supported what Daytime said and shared her experience to get a job after she graduated from high school:

One of the things I experienced when I graduated from high school was trying to find, um, employment, and I got discriminated several different times. Mm, from different companies just because I was blind, and they made it very obvious without just saying it. That's what it was. Of course, they bothered me, but I didn't let it stop me. I had to keep pushing myself until I find what I was wanting to do. And it had got to the point that, I was just looking for anything rather than I wanted to do a like to do. I just wanted employment because I wanted to be independent and be on my own. And I did not want to go back home, because I'm from a very small hometown and they don't have anything that has accessibility there for disabled people. So, I kept pushing myself until I was able to find employment.

Guerrero (2017) suggested that it is up to individuals who are VI to educate employers about VI so they feel better equipped to work with VI in work place. Two of the participants, Dahlia and Steve emphasized that they did not have to "beg for a job." My field notes indicate that their voices were full of pride saying it. Next, I will address the theme of the Material Well-Being and some of the lived experiences that participants revealed for the theme. The theme sensitive so purposefully, I left close to the end of the interview. and some of the lived experiences that participants revealed for the theme.

Material Well-Being

As my pilot subject, Laura, shared in her interview, material well-being is connected with stability, security and safety and all the things that make us comfortable, but shelter is the biggest that gives the stability and well-being feelings of security. The Material Well-Being theme revealed two subthemes financial stability and housing. The question about financial stability is a sensitive question, and it was put late on the questionnaire (Maxwell, 2013 & Saladana, 2016). I defined financial stability as paying bills, having an emergency fund, and save for retirement. Participants were asked to describe their financial status. All the participants were given the choice if they do feel comfortable, they did not have to share any information. All the participants answered the question about financial stability and they all indicated that they are financially stable; have savings and retirement. I was very familiar with the home of one of the participants from previous connections. I was invited to the homes of two of the participants. For the interview and I picked up one of the participants at his home. Four of the homes were in very safe neighborhoods. Two of the other participants described their homes in the interviews. Steve shared in his interview that his home is very accessible and comfortable for him:

My home is a ranch 2400 square feet. It's a monstrous house that I no longer really need but, it's laid out and it was designed with some accessibility features in mind. At that point, I had some residual vision, so I made sure that I had some high contract stuff going on that didn't really impact the decor. Um, materially. It's a very nice home, as compared to other homes in this community is very

comfortable. The standard of living that I have achieved for myself is very, very comfortable for me.

Summer described her home as “her dream home”:

I am a home owner. I moved in my new home about almost three years now. We have five bedrooms, 4.5 baths and a recreation room. I have a fenced backyard and we just had a pool installed, this summer. And we have a hot tub, too. So, I really love my home. I'm happy that I bought it. This is my second home, um, as a homeowner.

All the participants of this study are homeowners. My field notes indicated that all of them are very proud of being homeowners. In summary, the themes that emerged in the participants' data analysis of the Well-Being factor are (1) Emotional Status, (2) Health and Fitness, (3) Accessibility of work and home, (4) Employment, and (5) The Material Well-Being. Next, I will discuss the unanticipated findings of my study.

4.4 Unanticipated Findings

There were two unanticipated findings in my study (1) clinical trials or surgeries to restore vision and (2) one participant buying her own car to resolve problems with transportation. During the analysis of Dahlia's and Summer's transcripts, the unanticipated theme of clinical trials emerged. Sharing their stories was a very emotional experience for both of them. From my experience as a TVI, many children or adults who are blind go through surgeries or clinical trials to restore vision. I did not encounter anything in the literature review to support this finding. My field notes and memo indicate the Dahlia touched her guide dog and paused for thirty seconds before sharing her story:

I think it is important, especially if you are trying to reach parents. I am looking for words here, [PAUSE] the most depressed that I have been in my entire life, the thing that put me down to a place that I had to go seek professional counseling, it was after [PAUSE] a clinical trial trying to cure my vision. And it did not work, and I contributed to the research, and I am glad I did. I am glad that I went through it because I always will wonder, “Could it get fixed? Let’s go find out.” I didn’t get my vision restored, but at least I contributed to maybe the next generation, or the generation after that. I think so many times people get a diagnosis, and the first thing to do is, “It’s broken, we need to fix it.” And they forget to go and learned some alternative techniques. And, we forget to remind ourselves, actually, I am not broken, I am fine, and so it is really a tight rope; I am sure it’s a different balance for each individual, balancing that. I am going to keep an eye on the research, I am going to keep an eye on what they are doing, but at the end of the day, I am fine. Does it make any sense?

Summer had her first cataract surgery when she was six months old, and had multiple surgeries after that. Summer lost her vision at age 14, at the SCSD in one of dormitories, shared a very personal and emotional experience in our interview. Summer’s story: “I woke up four o’clock in the morning to go to the bathroom, and when I turned my bed light on, I couldn’t see. And then when I turned the bathroom light on, I still couldn’t see. And then I realized that ... [PAUSE] the vision was gone.” Summer shared that going through surgeries affected her so much that when the doctor suggested her son to have surgery, she did not agree to put her son through surgeries. Summer found out

from her mother later in life, that the doctors knew that her vision would not be restored but they wanted to try.

Dahlia's suggestions to parents who have children with a visual disability:

Listen to the doctors, pay attention that when a child is going through surgery, recovering through surgeries, and dealing with all of that, they are not learning Braille, they were not learning how to go navigate their neighborhood, they were not making friends, they were not doing things that they should be doing. SCSD, certainly, academics are there but what they do best is for the students to learn to be blind. So, kids are going to do academics, learning to be blind, and deal with the medical stuff? There is not enough time in the day! What suffers the blind skills!

This finding suggests the support that students will need from the family, TVIs and other professionals if they go through surgery that may affect, as Dahlia shared in her interview, their "blind skills". The stories shared by two of the participants and their advice for the parents are powerful.

Another unanticipated finding was Carolina Girl buying her own car to solve her transportation problems:

I know other blind folks that have bought their own cars. But, you know, I've kind of been on that teeter-totter with that and decided, I'm going to do it. And, you know, I made up my mind, and it's been so easy, much easier to say, "Hey, can you drive my vehicle?" than, "Hey, can I, four of us or three of us riding your vehicle?" So, I mean, all you're really paying is now is their time. It's not the

maintenance on their vehicle. It's not the gas in their vehicle chores. You're paying them for their time.

This finding may be familiar to other people, but it surprised me. I did not find in the literature review or encounter during the years working as a TVI. In the future, it will be interesting to see the concept “paying for their time” will have in transportation for the individuals who are blind or visually impaired.

In conclusion, I analyzed the data using Interpretative Phenomenological Analysis (IPA) and followed its characteristics (a) moving from what is unique to a participant to what is shared among the participants, (b) description of the experience which moves to an interpretation of an experience, (c) I committed understanding the participant’s point of view, and (d) focused on each participants’ lived experiences within a particular context. Data analysis consisted of identifying themes, phrases, descriptions, in the participants’ transcripts. I revealed several themes and patterns from the participants’ responses and transcriptions and developed a set of twenty-one themes and descriptive comments from the interview transcripts. Themes and patterns were used to establish experiences most frequently shared by participants in the study. By applying a hermeneutic phenomenology approach, I examined the text to reflect on the context to discover something “telling,” “meaningful,” and “thematic” (Sloan & Bowe, 2014). I found “commonalities among participants in addition to what was unique about each individual” (Joseph, 2010, p. 118), I “wrote” a story that captured significant and meaningful lived experiences of the adults who are blind. My phenomenological study created a “blended story” (Starks & Trinidad, 2017) that I hope it will give the readers the feel what it means to live in the world as an adult who is blind. Next, I will present the

summary of the findings, risks and benefits, limitations and considerations of the study, significance and contributions, implications for further research.

CHAPTER FIVE

DISCUSSION

The research question, “How do adults who are blind describe their QOL?” was answered by the participants’ significant and meaningful lived experiences of QOL that they shared in our interviews. Through the analysis of the data twenty-four themes were identified (see Table 18). One of the common themes that the participants responses provided was growing up with supportive families. Family support and involvement are essential to the development of child who is blind or VI and their success in life. All the participants provided evidence that family support is critical growing up with a visual disability. It is important to mention that the participants’ parents never adopted the attitude “You are blind, you cannot do it.” Instead, parents supported the participants to maintain their independence and pushed them hard to achieve goals like their other children. This finding supports Kef (1997) and Carlson et al. (2010) findings that parents and family members are the primary sources of positive, emotional, and practical support for their children and adults who are blind or VI.

The data analysis revealed that participants’ self-determination, self-advocacy, and self-motivation skills had an impact in their life experiences and their QOL lived experiences. The importance of the self-advocacy skills starting at a young age was recognized by all the participants. As Daytime shared in his interview, it was important for him at a young age “learn to speak up” and to self-advocate. Also, self-advocacy skills were important for participants’ success in college and life. Guerrero (2017)

supported the transferability of self-advocacy skills from high school to college or work on her study.

The participants' responses provided evidence that it was vital for them to get a good education. As Daytime mentioned in the interview, all people who are blind are capable of doing all the things that sighted people do "if they are taught how to do it." As Dahlia stated in her interview: "A good education increases your chances for success in the future." What participants have in common, they all dedicated their success in life to reading and writing in Braille at a very young age.

Additionally, the role of the TVI and their dedication, support for parents, service delivery, and resources they provide impacted the QOL of adults who are blind. Also, public school teachers and their attitudes towards students who are blind or VI impacted their future life experiences as adults. Educational experiences through the public school or residential school settings play an essential role in their future life experiences. Guerrero (2017) found that TVI commitment was evident in in-service delivery, commitment, and efforts to prepare the students for the future. My findings support that that TVIs services to students and individuals who are blind and VI are fundamental for their future. Also, O&M training and how to travel safely are essential for individuals who are blind. As Daytime shared in his interview, when he refused to use a white cane in high school, but when he got to college in an urban area, he decided that he "wanted to live."

Independence was identified as an important factor in the QOL of the participants. Schalock and Verdugo (2012) identified independence as an important factor in the QOL of individuals with disabilities. All the participants valued their independence and were

proud that they lived independent lives. They are as independent as anyone else, but they get the information from four senses instead of five. The experience of having a Dog Guide was life-changing and improved the confidence, and health and fitness of two of the participants.

Support systems of the participants consisted of family and friends from church, work, neighborhood, and organizations that support individuals who are blind such as NFB. Those support systems were essential for the QOL of the participants. Data analysis revealed that asking for help was stressful, and all of them shared that they are sensitive to other's people time. All the participants provided information of their involvement in the organizations for the blind, such as NFB and the where they live or work.

Educating the community about blindness was a common concern in all the interviews. As Phoenix Jackson said in his interview, "I am pretty much other than not be able to see, able to do the same thing things they can do." Participants shared that one way you can educate other people is by talking to them or showing them what you can do; and teaching them that is it OK for their assistance to be denied. Social skills may influence how the individuals who are blind are accepted in society or work environment. Social interactions are a concern because they are visually rich encounters that individuals who are blind miss. Stereotypic behaviors or blindisms may play a role in the acceptance. Additionally, participants' attitudes and perceptions towards blindness play a role in their emotional well-being. All participants shared that they advocate for individuals who are blind or VI and they love to help by promoting fitness, ILS skills, transportation, and resources.

Transportation is the most significant barrier in the QOL of adults who are blind. This finding supports the previous research in the field of blindness and VI (Antonelli et al., 2018; Cimarolli & Boerner, 2005; McDonall, 2014). Furthermore, transportation remains one of the barriers to employment of people who are blind or VI. All the participants during the time when interviews took place reported that were employed. However, as Daytime stated in his interview, “it is not the blindness that creates the barrier, it is the lack of willingness and resources.”

All the participants continue to learn as adults through readings, professional developments, technology, and hobbies. The younger participants relied on podcasts, networking, and different apps. Accessing and keeping up with the new technology was considered important to learn as an adult. Also, learning new ILS skills improves the QOL of their lives.

Services in the communities where adults who are blind work and reside, such as Commission for the Blind, NFB, other nonprofit vocational services such as ABLE, help adults who are blind with training and to finding employment. Many services such as Uber, Lyft, and UberEATS are available, but as the participants noted in the interviews, they need to be more accessible for individuals who are blind or VI.

All the participants are registered to vote. One of the participants run for office and all of them are involved in the organizations for the blind in the communities where they work or live. The study outcomes on voting accessibility support Rosenblum et al. (2020) findings that there is no guarantee of accessibility at the physical polling location and the volunteers who work at the stations have trouble getting the voting interface to work and it takes time for them to figure that out. Rosenblum et al. (2020) reported that

25% of the 1,790 participants of the study knew about the accessible system for voting, and 1 of 10 participants have voted independently. In contrast all my study participants know about the accessible voting system and voted independently in the last election.

Two of the unanticipated findings were (a) clinical trials or surgeries to restore vision and (b) purchasing a car to resolve problems with transportation. These two findings are important to mention because students who go through surgeries or clinical trials will need support from the family, TVIs, and other professionals after surgeries and trials. Moreover, parents need to be prepared that may affect, as Dahlia shared in her interview, “blind skills.” Also, in the future, it will be interesting to see the concept “paying for their time” will have in transportation for individuals who are blind or visually impaired.

The findings above demonstrate areas of the QOL that impact the quality of life for adults who are blind and it resonates not only with the adults who are blind, but with a larger population of people who are VI. According to Holbrook et al., (2009), measurement of the QOL can help determine factors that have the most positive influence on the lives of people who are blind or VI that can be addressed in the educational and rehabilitation interventions. It is essential that TVIs and professionals who educate blind or VI students to understand the desired life outcomes from the adults’ perspectives. QOL factors, domains, and indicators are a response to these understandings.

QOL is a construct that attempts to define what it means to “live the good life” (Schalock & Verdugo, 2002, p. 351). As Laura summarized in our interview, that is significant: “Because tomorrow, when they wake up, it's not going to be important that they know the algebraic quotient. What is important is whether they are happy people,

and they're satisfied with their lives.” Next, I will address the risks and benefits of the study and its limitations and considerations.

5.1 Risks and Benefits

Considering the risks and benefits of my study enabled me to understand further the trust and authenticity I presented to the participants. The only risk that I anticipated was my working experience only in a residential school setting. I was aware that exploring the educational setting's weakness and the role it plays in the QOL of adults who are blind may create a risk in my employment. I minimized this risk by not involving staff who are blind whom I supervise. The participants were not at risk in any manner in my study. However, the study process and the results will be beneficial to the participants and all those who work with and support individuals who are blind. The study will benefit all students who are blind or VI by learning from the life experiences and QOL point of view of adults who are blind. My study will increase understanding of how adults who are blind describe their QOL through their lived experiences. The results of this study will also benefit parents and professionals in the field of blindness in making better placement decisions along the continuum of placement options in educating students who are blind in South Carolina.

5.2 Limitations and Considerations

One of the limitations of my study is the small number of participants. My study has only six participants, and all of them have a visual disability. Therefore, the generalization of the QOL for the general population may not be applicable. Since the generalization of the results is not one of my study goals, then the limitation is minor. In my study, the in-depth interviews were intended to provide a rich descriptive insight into

the QOL lived experiences of adults who are blind rather than identify a generalized phenomenon. Another limitation is that all the participants in the study are adults who are blind. The adults who are VI or legally blind are not included in this study. I selected adults who are blind for a variety of reasons. First, during the literature reviewed I noted that frequently the population of the children or adults who are blind are grouped together with children or adults that are legally blind or VI. The description of the QOL lived experiences of that population may differ from the lived experiences of adults who are blind. Second, I was inspired for the study by three individuals who are blind. I wanted to tell the life experiences and their story of QOL. Third, as a TVI, I had access to individuals who are blind, legally blind and VI. My goal was to address the group of the adults who vision disability is the hardest. The other groups of the population such as legally blind or VI can be compared with them in the future research. Next, I will discuss the significance and contributions of the study.

5.3 Significance and Contributions

The primary significance of this study comes through the qualitative aspect of the investigation of the QOL. By conducting the research qualitatively, data that I collected supplied rich life stories of the participants' lived experiences. My study shows significance by introducing the QOL theory to the decision-making process of educating individuals who are blind. To develop a good QOL in young adults and adults who are blind, it is essential for us as educators and professionals to understand their desired outcomes. This study served as a platform for six participants who are blind to describe their QOL through their lived experiences. QOL research is one way to understand how adults who are blind describe their QOL from their lived experiences. Community

services, families, teachers, social workers, and guidance counselors need to consider QOL outcomes for their students and clients who are blind. Understanding what adults who are blind believe is vital to their QOL will help parents, guardians, educators, and professionals in the field of VI to make better education placement decisions for children who are blind. Additionally, this study's results and findings contribute to new knowledge regarding the QOL lived experiences of people who are blind and to QOL literature. Next, I will discuss my own subjectivity and positionality and ethical issues of my study.

5.4 My Own Subjectivity and Positionality

Throughout the research process, I acknowledged my own subjectivity and positionality and monitored it by using: member checks, peer debriefing, intensive interviews, verbatim transcripts, triangulation methods of data collection, and my own field notes and memo documentation. My subjectivity and positionality were both a tremendous strength and a potential weakness for my study. By identifying my subjectivity and positionality, I acknowledged my preformed prejudices, biases, and stereotypes. Through this lens, I “bracket” my own preconceptions about QOL and blindness throughout the study. I am a certified vision teacher and current community liaison at SCSDB. I worked directly with students and adults who are blind for twelve years, and more recently, I am very involved in the process of admissions of the new students. Also, I am associated with various associations and service organizations for adults and children who are blind or VI, such as AER, the State Vision Summit, and the Commission for the Blind.

Additionally, through the years I have had many opportunities to meet many adults who are blind or VI and graduated from either a residential or a local school setting. Therefore, a great strength that carried to my study was being a well-trained professional in the field of education of children who are blind or VI. At the same time, I acknowledged that by working only in a residential school setting, I have limited experience working with students who are blind and attend public schools. My subjectivity in this study was highly dependent upon my belief that every child who is blind can be educated and become a contributing member of society. The strength of my positionality in the study was that of building positive relationships with people. I have professional and social relationships with four of the study participants, and during the research process I developed relationships with the other three participants. These relationships strengthened my study. I purposefully selected the participants in the study from different ages, races, and genders in order not to impact my subjectivity in the process.

There were two personal differences (a) education backgrounds and (b) vision that did not impact my study. As a teacher working at SCSDB, I am an insider. I am one of the professionals in the field who helps educate students to have a good quality of life as they become successful members of society. I was professionally equipped to do this study because I am educated in the field of vision. I have helped many young adults who are VI or blind transition to work or college, and I have a voice in the field of educating students who are blind or VI. But at the same time, as a researcher, I am an outsider in the “world of blindness” that is, I can see. I am not “one of them” in this respect. Because I have worked for twenty-six years in a residential school setting, I am aware that I must

pay diligence to avoid potential bias in both my relationships and students' accomplishments based on where they were educated.

I monitored the impact of my subjectivity and positionality throughout the research process by using tools and methods such as member checks, peer debriefing, intensive interviews, verbatim transcripts, triangulation methods of data collection, and my own memo documentation. According to Maxwell (2013), member checks are one of the most critical ways of ruling out the possibility of misinterpreting the meaning of what participants' perspectives, words, and actions. Also, peer debriefing was significant. I had two professional peers who reviewed my writings. Intensive, semi-structured, in-depth interviews and observations helped me to collect data that was detailed and varied enough to provide a full and informative picture of my study. Besides, I provided a verbatim transcript of the interviews and detailed descriptive notes of the participants' behaviors and responses during the interviews. I used a triangulation method of collecting data through interviews, field notes observations, and documentation of the participants' visual impairment etiologies. Next, I address the ethical issues and study implications, limitations and considerations, and significance and contributions.

5.5 Ethical Issues

The ethical issue of anonymity is ensured by the qualitative methodology I have chosen. That is, my research did not harm the participants in the study because the information I collected from the interview questions were their own responses from life experiences, perspectives, and achievements. During each interview, I clearly stated the purpose of the study and the participants' role. I ensured confidentiality by explaining my use of the data, results, and conclusions. Also, during the interviews, I assured all

the participants that their identities will be kept confidential. Being authentic to the intent of this study was also an important ethical issue. Authenticity grew out of the participants' trust in me and the positive relationships and rapports that I have built or formed with them. Understanding my participants' perceptions of my study was instrumental for my research to develop a "useful and ethically appropriate relationship with them" (Maxwell, 2013, p. 93).

Another priority that I had was to make all the participants in the study feel very comfortable with me and the research process. I conducted each interview at his/her place of choice, and I arranged their desired transportation. Also, each participant was rewarded with a gift card (value \$50.00) at the end of the interviews. I sent them all a thank you braille card and included the gift card of their choice. My primary ethical obligation was to put myself in my participants' positions and ask how I would feel if I was one of them. I prepared notes before each interview in anticipation of the questions that participants may ask. Next, I will discuss implications for further research and how the study affected me as a researcher.

5.6 Implications for Further Research

My study and its findings increase the understanding of how adults who are blind describe their QOL through their lived experiences and will contribute in the research of blindness and VI. Further research will need to address the adults who are legally blind or visually impaired.

Another area of the interest it will be to address of the population who have lost their vision late in life due to ageing. As Steve suggested in his interview, "There is a difference between people who lose their vision later in life and people who grew up

blind or VI.” Another study may address how people who become blind later in life describe their QOL and compare that with the people who are born blind or VI. Additionally, three questions should be added to the Questionnaire of QOL (1) Do you have/had a guide dog? (2) What would you like for the average person to know about blind people? and (3) What advice would you give a young person who is blind or VI? Next, I will conclude with my last thoughts about the study and how it impacted me personally as a researcher.

5.7 Researcher’s Role

In conclusion, I arrived at the “doorsteps” of this research after years review of the literature of QOL theory and qualitative research inquiries. The research question for the study was outlined and conceptualized according to the review of the exciting literature in the field of blindness and VI, qualitative research, QOL theory, and the researcher’s professional experience as a TVI. My study addresses a specific group of the population that we need a “complex, detailed understanding of the essence” (Creswell, 2007) of the QOL topic. I conducted a phenomenological quality research study to answer my research question of how adults who are blind describe their own QOL. The settings and six participants were appropriate for my study. The methods that I used provided the data that I needed to answer the research question. I collected data by asking open-ended questions, observed, wrote field notes and memos, and listened to the life stories of the participants. The study's findings and outcomes are a collection of descriptions of the lived experiences that participants provided. Their voices carry the story in understanding the QOL lived experiences and what it means to live as adults who are blind in the world.

According to Saldana (2016) it is important for the researcher to write about how the researcher has been influenced and effected by the study. As a TVI and administrator in the field of VI, I am very grateful that I did a qualitative study. I am very touched by the life experiences of the participants and their willingness to share their life stories. Through the years, I have developed professional and personal relationships with four of the participants, including the pilot study participant. Through this study, I met three extraordinary individuals that I did not know but they were very gracious to trust me to tell their life experiences and stories. I look forward to more professional and personal relations with them for years to come. My study gave voice to six participants' life experiences and their understanding of QOL from their perspectives. I shared the story of their life experiences in the findings of the study and provided an interpretation of their understandings on QOL. I will end the study with a quote that my friend Laura said in her interview, "What really matters in the long run, is the quality of your life that is what matters most."

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APPENDIX A

DEFINITION OF TERMS

Blindisms: Several terms are used to describe these behaviors such as stereotypical behaviors, repetitive behaviors, mannerisms, self-stimulatory behaviors which include: eye poking or pressing, hand flapping, rocking, light gazing, and head shaking.

Expended Core Curriculum (EEC): Curriculum designed to meet the unique needs of students who are visually impaired or blind. The curriculum covers nine topics:

Compensatory and functional skills, orientation and mobility, social skills, independent living skills, leisure and recreation skills, career and vocational skills, technology, sensory efficiency, technology, and self-determination.

Quality of Life (QOL): Quality of Life is defined as an individual's perception of his/her position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns (World Health Organization QOL Group, 1995, p.1405).

Individualized Education Program (IEP): Individualized Education Program designed for students who receive Special Education services, ages 3-21 years old.

Orientation and Mobility (O&M): Program that focuses on instructing individuals who are blind or visually impaired for safe and effective travel through their environments.

Support System: A network of people who provide an individual who is blind or VI with practical and/or emotional support.

Orientation and Mobility (O&M): O&M training teaches individuals with VI to travel safely, efficiently, and independently in various environments. O&M specialists help people get around a variety of environments: home, community, church, school, etc.

Teacher of Visually Impaired (TVI): TVI is a teacher (states vary on the criteria for certification as a TVI) who meets the educational needs of students who are blind or have visual impairments ages birth to 21 years old. The role of TVI is to provide direct and/or special consultative education services specific to vision loss. TVI provides support to students, teachers, and parents and acts as a liaison with community services.

Visual Impairment: Individuals whose visual acuity is 20/70 in the better eye with correction or the visual field is less than 20 degrees. It includes (a) Legally Blind: Adults whose visual acuity in the better eye with correction is 20/200 or the visual field is less than 20 degrees (b) Light perception: Individuals who have only light perception, and (c) Totally Blind: Individuals with no light perception.

APPENDIX B

TAPEACALL

TapeAcall is an American communications technology that provides videotelephony and online chat services through a closed-based peer-to-peer software platform and is used for teleconferencing, telecommuting, distance education, and social relations. Beginning in early 2020, Zoom's software usage saw a significant global increase following the introduction of quarantine measures adopted in response to the COVID-19 pandemic.

APPENDIX C

INVITATION TO JOIN THE STUDY

Dear participant,

My name is Loreta Dylgjeri. I am a doctoral student in the Education Department at the University of South Carolina. I am conducting a research study as part of the requirements of my degree in Special Education-Leadership, and I would like to invite you to participate. This study is sponsored *by the Department of Education* at the Universality Of South Carolina.

This research intends to explore the Quality of Life (QOL) of adults who are blind. The aim is to advance the research in the area of blindness and enhance the research in the Quality of Life.

If you decide to participate, you will be asked to share life experiences based on the Quality of Life domains and indicators such as personal development, social participation, independence, social inclusion, emotional, physical, and material well-being. Also, you will be asked to meet with researcher for two interviews and write a summary of the etiology of your visual Impairment.

In particular, you will be asked questions about your life experiences, beliefs, attitudes, and understandings of QOL. You may feel uncomfortable answering some of the questions. You do not have to answer any questions that you do not wish to reply to. The meeting will take place at a mutually agreed upon time and place, and should last about 60 or 90 minutes. The interviews will be recorded so that I can accurately transcribe what is discussed. The transcripts of the interviews will only be reviewed by members of the research team and destroyed upon completion of the study.

Participation is confidential. Study information will be kept in a secure location. The results of the study may be published or presented at professional meetings, but your identity will not be revealed. You will receive a \$50.00 gift card for participating in the study.

I will be happy to answer any questions you have about the study. You may contact me at (864) 384 -4736 or by e-mail at ldylgjeri@scsdb.org.

Thank you for your consideration. If you would like to participate, please contact me at the number or e-mail listed above.

With kind regards,

Loreta Dylgjeri

Loreta Dylgjeri

APPENDIX D

CONSENT TO BE A RESEARCH SUBJECT

TITLE OF RESEARCH: HOW DO ADULTS WHO ARE BLIND DESCRIBE THEIR QUALITY OF LIFE?

KEY INFORMATION ABOUT THIS RESEARCH STUDY:

You are invited to volunteer for a research study conducted by Loreta Dylgjeri. I am a doctoral student in the Department of Education, at the University of South Carolina. The University of South Carolina, Department of Education is sponsoring this research study. The purpose of this study is to increase understanding of how adults who are blind describe their Quality of Life (QOL) through their lived experiences. You are being asked to participate in this study because you are an individual who met the following criteria (a) a diagnosis of blindness, (b) between the ages of 19-65 years old, (c) no additional disabilities except visual impairment, and (d) willingness to participate in the study. This study is being done in South Carolina (SC) and will involve approximately six volunteers.

The following is a short summary of this study to help you decide whether to be a part of this study. More detailed information is listed later in this form.

PROCEDURES:

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

1. Complete a short history of the etiology of your visual Impairment.
2. Complete an interview about demographic information.
3. Complete an interview about QOL domains.
4. Have your interview recorded in order to ensure the details that you provide are accurately captured.

DURATION:

Study will be conducted over a period of 90 days.

RISKS/DISCOMFORTS:

This study will not create any risk or discomfort for any of the participants.

BENEFITS:

Taking part in this study is not likely to benefit you personally. However, this research may help researcher to better understand Quality of Life of adults who are blind.

COSTS:

There will be no costs to you for participating in this study other than your time.

PAYMENT TO PARTICIPANTS:

You will be paid \$50.00 gift card to your favorite store or restaurant for participating in this research study. The card will be given to you at the last meeting or mailed to you.

CONFIDENTIALITY OF RECORDS:

Information obtained about you during this research study will remain confidential and released only with your written permission. Study information will be securely stored in locked files and on password-protected computers. Results of this research study may be published or presented at seminars; however, the report(s) or presentation(s) will not include your name or other identifying information about you.

CONFIDENTIALITY CERTIFICATE:

To help the researcher to protect your privacy, she has obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers can use this Certificate to legally refuse to disclose information that may identify you in any federal, state, or local civil, criminal, administrative, legislative, or other proceedings, for example, if there is a court subpoena. The researchers will use the Certificate to resist any demands for information that would identify you.

VOLUNTARY PARTICIPATION:

Participation in this research study is voluntary. You are free not to participate, or to stop participating at any time, for any reason without negative consequences. In the event that you do withdraw from this study, the information you have already provided will be kept in a confidential manner. If you wish to withdraw from the study, please call or email the principal investigator listed on this form.

I have been given a chance to ask questions about this research study. These questions have been answered to my satisfaction. If I have any more questions about my participation in this study, I am to contact Loreta Dylgjeri at (864) 384 - 4736 or email at ldylgjeri@scsdb.org

Concerns about your rights as a research subject are to be directed to, Lisa Johnson, Assistant Director, Office of Research Compliance, University of South Carolina, 1600 Hampton Street, Suite 414 D, Columbia, SC 29208, phone: (803) 777-6670 or email: LisaJ@mailbox.sc.edu.

I agree to participate in this study. I have been given a copy of this form for my own records.

If you wish to participate, you should sign below.

_____ Signature of Subject / Participant	_____ Date
_____ Signature of Qualified Person Obtaining Consent	_____ Date