

Qualitative Investigation of the Experience of Quality of Life for Young Adults Who  
Are Blind

by

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## **ACKNOWLEDGMENTS**

Within this dissertation, among many other facets of the lives of six amazing young adults, I describe several participants' appreciation for the pastime of "getting lost." For a young adult who is blind, this means taking off from a known starting point and then willingly letting fate and the environment lead you to new people and places. Getting lost requires trust in others and in yourself as well as the knowledge that you will probably be changed – for better or for worse – before you make your way home from the experience.

In putting into words my doctoral journey and the people who have supported me, I am smiling at the parallels between my experience and my participants' descriptions of "getting lost." To begin with, I could never have left home – literally or figuratively – without the support of my husband, Mark Sheffield, who demonstrated unconditional faith, love, and optimism while I ventured forth to Lubbock and beyond in search of a yet-to-be-defined adventure. My parents, Doug and Cindy Mackiernan, were also always a phone call, email, or two-day drive away when I needed advice or thorough proof-reading.

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Finally, looking ahead to future adventures and back at where I have been, I know that I am not the first and will not be the last explorer to set out to “get lost” and see what happens in pursuit of an ambitious goal. When I was much younger, I undertook to write about the adventurer Hernando de Soto and his search for a city of gold, not realizing until several hand-written pages later that I was being far too descriptive for the five-page requirement of my elementary

school research report. I wanted to stop midway through and write “... and he died,” but my advisors (Mom and Dad) did not approve. Similarly, today, this paper is quite a few pages longer than I had originally envisioned – but it would not do, not then and not now, to stop the adventure prematurely! And, even though these five chapters are now complete, there is still so much more to be done with this line of research and with my life. Thanks again to everyone who encourages me to keep going! God bless!

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## ABSTRACT

Globally and locally, disability advocates seek ways to identify promising programs and services. “Best practices” is a buzzword not only for educators, but also for agencies hoping to invest their development dollars effectively. Yet, we cannot promote best practices unless we can answer the question, “best practices for what?” What outcomes do people with disabilities value?

Quality of life (QOL) is an important and measurable outcome which should become a basis for best practices in education, disability rights, and development. Researchers have proposed theories and instruments for measuring QOL but have not validated their theories and instruments for populations that include people with visual impairments. In order to validate instruments or theories, we must have a theory of QOL for people who are visually impaired; therefore, I undertook an exploratory investigation of the experience of QOL for young adults who are blind. I conducted in-depth interviews with six young adults and analyzed the transcripts, identifying six themes: *external support system*, *experiences*, *interdependence*, *independence*, *internal support system*, and *knowledge and skills*. These themes and their subthemes have immediate applications for education, community services, and advocacy.

This research offers a starting point for an array of studies. Additional qualitative research will enhance the proposed model of QOL, enabling instrument validation and larger-scale studies in populations that include people who are visually impaired. Existing QOL instruments should be reconsidered in the light of evidence about QOL as experienced by people who are blind; then

these tools can be redesigned to ensure validity.

My methods and findings demonstrate that the voices and experiences of people with disabilities can and must guide evaluation and research. In response to the United Nations Convention on the Rights of Persons with Disabilities, a few studies and reports have described effective practices in international disability rights, but none have employed rigorous methods necessary to demonstrate evidence-based practices and none have emphasized QOL as an indicator. This study unites research from the field of visual impairment with the work of QOL and disability scholars, strengthening the research basis for QOL to promote the rights of all persons with disabilities.

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## **LIST OF ABBREVIATIONS**

ADA	Americans with Disabilities Act
AT	Assistive Technology
COMS	Certified Orientation and Mobility Specialist
DPO	Disabled People's Organization
ECC	Expanded Core Curriculum
EFC	European Foundation Center
EU	European Union
IASSID	International Association for the Scientific Study of Intellectual Disabilities
NGO	Non-Governmental Organization
O&M	Orientation and mobility
QOL	Quality of Life
QOL.Q	Quality of Life Questionnaire (Schalock & Keith, 1993)
QSLQ	Quality of Student Life Questionnaire (Keith & Schalock, 1995)
SIRG-QOL	IASSID's Special Interest Research Group on Quality of Life
TVI	Teacher of the Visually Impaired
UN	United Nations
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
WHO	World Health Organization
WHOQOL	World Health Organization's Quality of Life Assessment (1995)

## CHAPTER I

### INTRODUCTION

Across the globe, people with disabilities are increasingly engaging with and being supported by advocates, researchers, and politicians. Through national and international organizations, they collaborate to end exclusion, oppression, and apathy. To realize the greatest benefits from these diverse efforts, the international community must establish processes and tools for evaluating the efficacy of disability rights interventions, and such evaluations must be used to identify and promote the most productive and efficient interventions.

This study builds upon existing research which has demonstrated that the construct *quality of life* (QOL) is an appropriate outcome measure for interventions related to the 2006 United Nations Convention on the Rights of Persons with Disabilities (Karr, 2011; Verdugo, Navas, Gómez, & Schalock, 2012). Recognizing that existing QOL instruments have not been rigorously validated for use with persons with visual impairment, and noting the lack of a theoretical basis for QOL as experienced by persons who are visually impaired, I conducted exploratory, qualitative research using interviews and thematic analysis to develop a theoretical model for QOL as experienced by young adults who are blind.

#### **Background of the Problem**

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) is the latest in a line of international disability treaties and is the first treaty to be enforceable and binding upon ratifying nations. At present, most efforts to evaluate the implementation of the UNCRPD and related interventions have been *pan-*

*disability*, meaning that they attempt to judge the impact of the treaty for populations of people with various disabilities using a single process. Leonard Cheshire Disability (Rieser, 2012), the European Network on Independent Living (Jolly, 2010), and the European Foundation Centre (2010) have conducted pan-disability UNCRPD implementation evaluations involving qualitative case-studies and mixed-methods designs. Additionally, all States Parties to the UNCRPD are required to provide the Committee on the Rights of Persons with Disabilities with a regular report of their treaty implementation progress; however, there is no empirical standard or required formatting for these national reports.

Some researchers, particularly those associated with the Special Interest Research Group on Quality of Life (SIRG-QOL) in the International Association for the Scientific Study of Intellectual Disabilities (IASSID), have connected their research into the construct of QOL with UNCRPD implementation (Karr, 2011; Verdugo et al., 2012). They found that the SIRG-QOL's theoretical model of QOL and the associated Quality of Life Questionnaire (QOL.Q) developed by Schalock and Keith (1993) are a good fit with the human rights detailed in the articles of the UNCRPD. Likewise, the World Health Organization (WHO) has developed both a QOL instrument for use with persons with disabilities and a detailed process for introducing and modifying this instrument in new cultures and contexts (World Health Organization Division of Mental Health and Prevention of Substance Abuse, 1997). QOL – which has various definitions but generally involves the extent to which a person's needs and desires are satisfied by the circumstances in which they live – is well positioned to become a valid and reliable outcome measure upon which to



evaluate implementation of the UNCRPD and related, international disability-right interventions.

Unfortunately, none of the existing pan-disability UNCRPD implementation studies has included a rigorous validation of a QOL instrument with persons who are visually impaired, leaving a major gap in the utility of these instruments for studying QOL in populations that include persons with visual impairments. Rimmerman and Morgenstern (2003) used the QOL.Q in their study of adults with visual impairment in Israel but did not discuss its validity for the population. Verdugo, Prieto, Caballo, and Peláez (2005) also employed the QOL.Q in their study of adults with visual impairments in Spain, attempting to report on the instrument's usefulness both with Spaniards and with persons with visual impairments. They reported concerns with the factorial structure of the CRPD but did not provide statistical evidence to distinguish the impact of using the QOL.Q the country of Spain from the impact of its use with persons with visual impairments.

The field of special education provides relevant research and discussion of the rationale for and challenges of validating instruments for use with persons with visual impairments. Geisinger (1994) warned that "we should attempt to perform a validation study whenever a test is modified or extended to a new modality" (p. 135). This statement is supported by Reid (1998, 2000) and Loeding and Greenan (Loeding & Greenan, 1998) who uncovered significant problems with instruments (standardized assessments) commonly used in schools and applied to students who are blind or visually impaired without prior consideration of their validity for this population. Loeding and Greenan and Geisinger also advocated statistical processes for evaluating

the validity and reliability of instruments, processes which rely on existing instruments and theoretical frameworks about the meaning of construct under investigation.

In the absence of any existing, validated instruments or theoretical explanations of QOL as experienced by persons who are visually impaired, the first step in studying the validity of the existing pan-disability QOL instruments is to develop a theoretical framework of QOL specific to the population of persons with visual impairment. Qualitative research is well suited to exploratory investigation and theory development; therefore, I conducted a qualitative study designed to yield themes in the experiences of QOL by young adults who are blind.

Research questions for the proposed study include a primary question, “What is the essence of “quality of life” as experienced by young adult students who are blind and enrolled in post-secondary educational programs?” and two secondary questions, “How is the essence of quality of life as experienced by young adult students who are blind influenced by the student’s primary and secondary school experiences?”, and “To what extent is the essence of quality of life experienced by young adult students who are blind similar to/different from the theoretical models, constructs, and indicators of quality of life present in existing quality of life instruments and research?”

This study incorporates a phenomenological framework, appropriate for research which deals with questions of meaning-making and the essence of experience in order to uncover a deep understanding of participants’ lived experiences (Smith, Flowers, & Larkin, 2009). The participants, young adults in post-secondary programs, shared their thoughts and experiences relevant to QOL, and the transcribed interviews

were analyzed for themes. The resulting analysis includes useful data about the thoughts and experiences of students with visual impairments as well as a possible theoretical model that can be improved by further qualitative research and tested through quantitative studies.

### **Statement of the Problem**

An existing gap in the knowledge of QOL, specifically, the absence of a theoretical framework for QOL as experienced by persons with visual impairments, prevents researchers from rigorously validating any existing QOL instruments for use in populations that include persons with visual impairments. Such a theoretical framework could be used to validate existing instruments or develop and test new, appropriate instruments, enabling the crucial inclusion of persons with visual impairment in studies of the implementation of international interventions to improve the rights of persons with disabilities.

### **Purpose of the Study**

Through this research, I aim to provide researchers, human rights organizations, educational advocates, and others with a better understanding of QOL for young adults who are blind. Through thematic analysis, I also explored differences in the understanding of QOL between students in different contexts. Ultimately, this has an initial contribution towards an improved quality-of-life measurement process that will enable national and international investigators to include participants who are blind in pan-disability QOL measurements within program evaluations. Valid, reliable instruments for measuring QOL will inform advocates, practitioners, and policy makers about the efficacy of interventions to improve the QOL of people with

disabilities.

Seeking the involvement of people with disabilities in the process of refining a measurement tool through qualitative questioning is respectful and empowering, in alignment with the transformative purpose of my research. Specifically, the study included purposefully selected participants (representing diverse demographic characteristics and educational backgrounds) from post-secondary educational programs in the southwestern United States, and their responses and reflections drove all data analysis and conclusions. My qualitative design will contribute to the social and cultural appropriateness (and validity) of any future, refined quantitative surveys which may be based in part off of this research, so that such surveys may be used with more diverse populations. Additionally, my use of qualitative methods permitted a broader description of students' experiences and perceptions (Punch, 1998).

Furthermore, qualitative research facilitates the inclusion of participant perspectives. *Personal and family orientation*, including the “involvement of individuals and families in the design, implementation and evaluation of QOL-related studies,” (Schalock, 2005, p. 695), and *methodological pluralism*, including the use of subjective and objective measurement techniques, are considered to be defining characteristics of QOL research by Schalock and other QOL researchers.

### **Significance of the Study**

This study was exploratory and qualitative; therefore, the methods and research questions were subject to revision throughout the research process. Although my intent was to develop a theoretical basis for a new or revised quantitative instrument, the participants' experiences provided insights beyond the construct of QOL. I have

explored these additional themes and discussed diverse implications. The themes uncovered in the analysis do provide a basis for a mixed-methods line of research, including future quantitative instrument development and dissemination, to assist the international efforts to develop evidence-based interventions for supporting persons with disabilities in achieving sustainable, subjectively and objectively improved life experiences.

### **Research Questions**

Primary question: What is the essence of “quality of life” as experienced by young adult students who are blind and enrolled in post-secondary educational programs?

Secondary questions:

1. How is the essence of quality of life as experienced by young adult students who are blind influenced by the student’s primary and secondary school experiences?
2. To what extent is the essence of quality of life experienced by young adult students who are blind similar to/different from the theoretical models, constructs, and indicators of quality of life present in existing quality of life instruments and research?

### **Research Design**

#### **Participants and Sampling**

I worked with six participants, which I determined during the analysis to be sufficient to achieve a saturation of themes in the analyzed data (Creswell, 2012). To increase homogeneity, I narrowed the larger population of persons with visual

impairments to the more consistent population of young adult students (ages 18-25) who are blind and who are attending post-secondary programs in the United States (college, vocational school, work-study programs, transition programs, etc.).

For the proposed study, participants had visual acuities ranging from presenting distance acuity of less than 20/400 to no light perception, in line with the World Health Organization's definition of blindness (2010a). This purposeful sample was gathered through my connections with state schools for the blind, state rehabilitation agencies, and national networks of young adults with visual impairments. All participants were from the southwestern United States.

### **Interviews**

Each participant was interviewed three times, each time in a face-to-face interview lasting between 49 minutes and 92 minutes. This three-interview format followed the recommendation of Seidman (2013), with the first interview considering the participant's life history, the second interview emphasizing details of the participant's experiences, and the final interview focusing on the meanings or understandings drawn by the participant from his/her experiences. For each interview, I used a semi-structured interview protocol based upon the protocols used by Poston, Turnbull, Park, Mannan, Marquis, and Wang (2003) in their constant-comparative study of *family quality of life* and by Borglin, Edberg, and Hallberg (2005) in their phenomenological study of QOL as experienced by older people. Prior to the interviews, draft interview protocols were shared with two colleagues who are blind and who work with young adults through rehabilitation programs in the same geographic region as the intended participants. Their feedback was incorporated into

the revised, final interview protocols. See Appendix A for protocols for the three interviews. I digitally recorded and transcribed each interview.

## **Analysis**

I employed MAXQDA qualitative data analysis software throughout the analysis of the interview transcripts. The nature of the data – with multiple and diverse opinions and experiences per participant – suggested a cross-case, thematic analytical approach, within which I considered important concepts arising from the entire collection of ideas and stories. In determining particular procedures for the analysis, I was influenced by Glaser's (1965) Constant Comparative Method for generating theory from qualitative data, including the coding of incidents within the data into potential categories (*codes*), integrating categories by comparing incidents and codes, and restricting the theory by developing thematic groupings of codes (*themes*). Like Glaser, Creswell (2012) suggested qualitative analysis should begin with a preliminary exploration of the data, followed by a coding process and the development, description, and interrelating of themes.

I read through each transcript a minimum of three times during and after the transcribing process, noting potential themes in my researcher's journal. Using MAXQDA, I assigned codes to segments of the transcript and tracked these codes in the software throughout the analysis of each interview, revising definitions of codes and incorporating new codes as necessary based upon the data. I engaged in constant comparison of codes, regularly returning to previously analyzed interview segments to apply new codes or revise existing codes. Following a rigorous coding of all transcripts (identifying over 2,300 significant text segments), I applied the constant

comparative approach across codes, reducing the number of codes and identifying a thematic framework which aligned with important patterns I perceived. The MAXQDA software's frequency counts and code co-occurrence tools aided in determining whether or not themes and categories under consideration were well supported by the data. The resulting, delimited themes arose both from among the particular codes and from across the interviews as a whole (as supported by notes in my researcher's journal and memos in the MAXQDA software system). The original transcripts as well as the themes and sub-themes were shared with participants so that they could provide feedback and/or suggest changes or corrections.

### **Theoretical Framework**

My research was exploratory and intended to develop theory; therefore, existing QOL frameworks were referenced with the understanding that the qualitative findings may not fit within any established theories of QOL. Having extensively reviewed literature on QOL as applied in diverse, international settings, I believed that the multi-dimensional, subjective, and objective understanding of QOL as contained in the theoretical model proposed by the IASSID's SIRG-QOL (Schalock & Verdugo, 2002) – which emphasizes that QOL is composed of the same constructs for all people – would be a good starting point for building an understanding of QOL for persons with visual impairments. However, I recognized that existing instruments built upon the SIRG-QOL's model might need to be modified in order to ensure their validity for use with persons with visual impairment.

My purpose was to directly study the lived experiences of young adults who are blind, and so my proposed study's methods were also influenced by



phenomenological theory. Phenomenology involves the study of experience. Husserl – the “father” of phenomenology – sought to better understand the “essence of experience” and, thus, also to better understand human consciousness (Smith et al., 2009). Other philosophers – Heidegger, Merleau Ponty, and Sartre – refined phenomenology by considering the multiple layers involved in interpretation. Any phenomenological analysis is tinged multiple times with the pre-conceptions and thought structures of various interpreters; therefore, phenomenological researchers should try as much as possible to “bracket” their own preconceptions in order to get closer to the actual experience of the participant.

### **Assumptions, Limitations, and Scope**

In this study of young adults with visual impairment, I assumed that participants would answer truthfully (according to their own interpretations of their lived experiences) to interview questions. My personal biases, including previous exposure to literature on QOL and prior experience and training as a teacher of students with visual impairments, were a limitation of the study; however, all qualitative research is interpretive, and the extent to which my biases led to perceptual misrepresentations has been addressed through an open dialogue about my preconceptions both in this dissertation and in my conversations with committee members. Furthermore, during data collection and analysis, I have consulted with the participants to ensure that their original intentions were maintained in the themes developed in my analysis.

Exploratory qualitative research is designed to uncover details and subjective experiences about the particular participants included in a study. The extent to which

the findings that emerge from the analysis can be transferred to other populations hinges upon the description and detail which I have provided to future readers. Through rich descriptions of participants and contexts, I hope that I have assisted future readers in determining if the experiences of the participants are relevant to other populations and situations.

I recognize that the six or more participants in the study could not presume to speak for all young adults who are blind and that the participants' geographic proximity most likely yielded similarities amongst participants that would not be expected in other geographic regions. Therefore, theories about QOL for young adults with visual impairment that have been generated by this study's analysis must be tested and re-tested through additional qualitative and quantitative studies including participants from around the globe.

### **Summary**

This chapter discussed the background, rationale, and methods for my study of QOL as experienced by young adults who are blind. Existing studies support the use of the QOL construct as an indicator of the success of international disability rights interventions. However, there is a need for a theoretical model of QOL for persons with visual impairments in order to validate existing QOL instruments or design a new instrument for use in populations that include persons who are visually impaired. The proposed study addressed this need using thematic analysis of semi-structured interviews. The findings improve our understanding of the lived experiences of young adults who are blind.

The following chapter provides an extensive background and rationale for this

research. I explain the need for evaluation measures for international disability rights interventions, discuss existing pan-disability evaluation efforts, and describe the challenges faced by researchers in ensuring the validity of such measures for populations that include persons with visual impairments.

## CHAPTER II

### REVIEW OF THE LITERATURE

Disability rights have recently received long-overdue attention at the international level, taking a well-deserved seat at the discussion table amongst important causes like women's rights, children's rights, and minority rights. The current international disability rights movement represents people from all walks of life and from all categories of disability, and most discussions and resolutions are *pan-disability*, approaching the rights of all disability groups together. Many of the most prominent and prolific research and advocacy groups, including Leonard Cheshire Disability, Inclusion International, and Disability Rights International, exemplify pan-disability collaboration, recognizing the shared experiences among those with orthopedic impairments, deafness, intellectual disability, etc. (Rieser, 2012).

With the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) (United Nations, 2006), a new line of research has developed to investigate countries' implementation of the UNCRPD and to help establish best practices for governments, non-governmental organizations (NGO's), and disabled people's organizations (DPO's) in achieving the desired human rights outcomes relevant to UNCRPD implementation (European Foundation Centre, 2010; Karr, 2011). The Committee on the Rights of Persons with Disabilities, charged with evaluating nations' implementation of the UNCRPD articles, has encouraged each ratifying country to establish monitoring groups and submit shadow reports alongside its official UNCRPD implementation report. With more detailed and representative reporting, the Committee will better understand what is and is not working in the

efforts to realize the equality of rights established in the UNCRPD (United Nations, 2006).

As with the international disability-rights movement, efforts to evaluate and understand UNCRPD implementation have been pan-disability, led in part by the Committee and many European organizations including Leonard Cheshire Disability (Rieser, 2012), the European Network on Independent Living (Jolly, 2010), and the European Foundation Center (2010). In the United States, the International Association for the Scientific Study of Intellectual Disability's Special Interest Research Group on Quality of Life and others (Lord, Guernsey, Balfe, & Karr, 2007; Verdugo et al., 2012) have begun to apply their existing research regarding *quality of life* as a framework for evaluating UNCRPD implementation, again with a pan-disability approach.

Despite the pan-disability emphasis evident in this evaluation research, the UNCRPD does provide for special recognition of the unique experiences and challenges of certain disability categories. In specifically addressing the needs for braille, orientation and mobility, and sign language, articles of the Convention draw attention to people with sensory disabilities and the specialized training and environmental adaptations which must be adopted in order to equalize access and participation (United Nations, 2006). In national debates over ratification of the UNCRPD, special consideration has arisen about the unique nature of sensory-related disabilities including the historical presence of special and self-contained schools for these populations and the unique communication methods and associated unique cultural traditions of people who are Deaf or blind. The United Kingdom's declaration

maintaining its intention to preserve special schools, contrary to the full-inclusion emphasis of Article 24 of the UNCRPD serves as evidence of this debate (*Convention on the Rights of Persons with Disabilities: Declarations and Reservations*, 2013).

As the United Nations (UN) Committee on the Rights of Persons with Disabilities continues to evaluate nations' reports on Convention implementation, and as the advocacy and research communities work to establish best practices for implementation, the pan-disability evaluation focus must also allow room for special consideration of people with sensory disabilities. Often these populations are the most difficult to survey as they require researchers with special skills (in braille or sign language) as well as connections to communities which are frequently isolated, hidden, and/or self-contained. "Pan-disability" surveys in reports may unintentionally or expressly exclude these populations under the unstated assumption that all disability groups benefit from the same best practices in implementation; yet this assumption can only be validated if researchers specifically study the unique needs of people with vision and/or hearing loss.

The following sections will review the existing literature on evaluating the implementation of the UNCRPD, particularly reports and studies which have connected human rights to measurable indices of quality of life. In particular, Schalock and Keith's Quality of Life and Quality of Student Life questionnaires (1993 and 1995) and the World Health Organization's Quality of Life Questionnaire will be described as important tools which have been validated internationally with a variety of populations. Additional research on QOL will be discussed, with a particular focus on relevance for persons with visual impairments. Finally, I will describe how a

theoretical model of QOL for students who are blind will enable testing of the validity of existing QOL instruments for use with persons with visual impairments. Validated QOL instruments will provide important benefits to non-governmental organizations, organizations of persons with disabilities, and governmental organizations seeking to develop research-based practices for implementation of the UNCRPD.

### **The UNCRPD**

The UNCRPD, ratified by the United Nations in 2006, was the first international human rights treaty of the twenty-first century, a testament to the international cooperation of nations, NGOs, and DPOs, and is a legally-binding commitment among countries to achieve true equality for people whom societies have historically cast out and forgotten. While previous declarations such as the Universal Declaration of Human Rights (United Nations, 1948) and the Declaration on the Rights of Disabled Persons (United Nations, 1975) acknowledged the issue of disability rights, the UNCRPD set forth a mechanism for holding the UN and States Parties accountable for making substantial legal and practical changes across the globe.

A State Party to the UNCRPD is a country, territory, or group of countries (such as the European Union) which has signed the treaty – agreeing to its principles – and ratified the treaty – consenting to be beholden to its implementation. As of May, 2014, 158 countries have signed the UNCRPD and 145 countries have ratified it, becoming States Parties (United Nations, 2014).

### **UNCRPD Articles**

The UNCRPD (2006) is comprised of 50 articles, many of which reflect the

treaty designers' focus on the United States' Americans with Disabilities Act (1991). The articles approach reforms from the perspective of the *social model of disability*, meaning that the authors and implementers view disability not as an individual problem to be fixed or overcome but as a socially constructed situation which must be changed by increasing accessibility, providing supports, and ending discrimination (Rieser, 2012). According to the social model of disability, someone who is disabled is not disabled by his or her condition; rather, he or she is disabled by the failure of the dominant forces in society to accommodate individual differences.

The preamble and first articles of the UNCRPD , 1 through 4, focus on describing this social perspective and laying out a new thought process and general obligations for considering disability rights. Articles 5 through 30 detail specific topics and focus points for advocacy and reform (see list of articles in Table 2.1).

Table 2.1

Articles in the United Nations Convention on the Rights of Persons with Disabilities

<u>Article No.</u>	<u>Title</u>
1.	Purpose
2.	Definitions
3.	General principles
4.	General obligations
5.	Equality and non-discrimination
6.	Women with disabilities
7.	Children with disabilities
8.	Awareness-raising
9.	Accessibility
10.	Right to life
11.	Situations of risk and humanitarian emergencies
12.	Equal recognition before the law
13.	Access to justice
14.	Liberty and security of person



*Table 2.1 Continued*

<u>Article No.</u>	<u>Title</u>
15.	Freedom from torture or cruel, inhumane, or degrading treatment or punishment
16.	Freedom from exploitation, violence, and abuse
17.	Protecting the integrity of the person
18.	Liberty of movement and nationality
19.	Living independently and being included in the community
20.	Personal mobility
21.	Freedom of expression and opinion, and access to information
22.	Respect for privacy
23.	Respect for home and family
24.	Education
25.	Health
26.	Habilitation and rehabilitation
27.	Work and employment
28.	Adequate standard of living and social protection
29.	Participation in political and public life
30.	Participation in cultural life, recreation, leisure, and sport
31.	Statistics and data collection
32.	International cooperation
33.	National implementation and monitoring
34.	Committee on the Rights of Persons with Disabilities
35.	Reports by States Parties
36.	Consideration of reports
37.	Cooperation between States Parties and the Committee
38.	Relationship of the Committee with other bodies
39.	Report of the Committee
40.	Conference of States Parties
41.	Depositary
42.	Signature
43.	Consent to be bound
44.	Regional integration organizations
45.	Entry into force
46.	Reservations
47.	Amendments
48.	Denunciation
49.	Accessible format
50.	Authentic texts

Importantly, the articles of the UNCRPD “[do] not recognize any new human rights of persons with disabilities, but rather clarifies the obligations and legal duties of States to respect and ensure the equal enjoyment of all human rights by all persons with disabilities” (Byrnes et al., 2007).

The closing articles, 31 through 50, outline a system of international cooperation, data collection, reporting and monitoring. The Optional Protocol to the UNCRPD (which 92 nations have signed and 78 have ratified) indicates consenting nations’ willingness to accommodate UN investigators, if necessary, to monitor their implementation of the treaty (United Nations, 2013).

**Article 24 – Education.** Although many articles of the UNCRPD touch on education-related issues, Article 24 is perhaps of most interest to special education researchers because of its concerted emphasis on people with disabilities’ educational rights. (See Figure 2.1 for the complete text of Article 24). Expectations for primary, secondary, and tertiary levels of education are described as well as requirements for teacher training. Strong emphasis is placed on inclusive education at all levels, mandating that States Parties enable students with disabilities to attend schools in their local communities (with reasonable accommodations) alongside their peers.

1. States Parties recognize the right of persons with disabilities to education. With a view to realizing this right without discrimination and on the basis of equal opportunity, States Parties shall ensure an inclusive education system at all levels and lifelong learning directed to:
  - (a) The full development of human potential and sense of dignity and self-worth, and the strengthening of respect for human rights, fundamental freedoms and human diversity;
  - (b) The development by persons with disabilities of their personality, talents and creativity, as well as their mental and physical abilities, to their fullest potential;
  - (c) Enabling persons with disabilities to participate effectively in a free society.
2. In realizing this right, States Parties shall ensure that:
  - (a) Persons with disabilities are not excluded from the general education system on the basis of disability, and that children with disabilities are not excluded from free and compulsory primary education, or from secondary education, on the basis of disability;
  - (b) Persons with disabilities can access an inclusive, quality and free primary education and secondary education on an equal basis with others in the communities in which they live;
  - (c) Reasonable accommodation of the individual's requirements is provided;
  - (d) Persons with disabilities receive the support required, within the general education system, to facilitate their effective education;
  - (e) Effective individualized support measures are provided in environments that maximize academic and social development, consistent with the goal of full inclusion.
3. States Parties shall enable persons with disabilities to learn life and social development skills to facilitate their full and equal participation in education and as members of the community. To this end, States Parties shall take appropriate measures, including:
  - (a) Facilitating the learning of Braille, alternative script, augmentative and alternative modes, means and formats of communication and orientation and mobility skills, and facilitating peer support and mentoring;
  - (b) Facilitating the learning of sign language and the promotion of the linguistic identity of the deaf community;
  - (c) Ensuring that the education of persons, and in particular children, who are blind, deaf or deafblind, is delivered in the most appropriate languages and modes and means of communication for the individual, and in environments which maximize academic and social development.
4. In order to help ensure the realization of this right, States Parties shall take appropriate measures to employ teachers, including teachers with disabilities, who are qualified in sign language and/or Braille, and to train professionals and staff who work at all levels of education. Such training shall incorporate disability awareness and the use of appropriate augmentative and alternative modes, means and formats of communication, educational techniques and materials to support persons with disabilities.

*Figure 2.1* The United Nations Convention on the Rights of Persons with Disabilities: Article 24 – Education

Article 24 outlines special provisions necessary for students with sensory disabilities (hearing and/or vision-related impairments) to succeed in inclusive

schools. These provisions include sign language (which must be developed and endorsed in many nations seeking to comply with the Convention), alternative and augmentative communication systems, and braille, as well as specialized teachers certified in the instruction of braille, orientation and mobility, and sign-language.

Article 24 has been a source of controversy among many ratifying nations (and among nations like the United States which have yet to ratify the UNCRPD), particularly because of its emphasis on inclusive education. The United Kingdom included a reservation in its UNCRPD ratification documents, specifically describing its intent to continue providing special schools for students with disabilities (United Nations, 2013). Many other countries which have ratified the UNCRPD without reservations on Article 24 have yet to shift their emphasis away from special schools for students with disabilities and towards serving students with disabilities in local school districts (see States Parties UNCRPD implementation reports, shadow reports, and Committee responses for China, Portugal, Qatar, and others [United Nations Office of the High Commissioner for Human Rights, 2013]).

### **UNCRPD Reporting**

Article 34 of the UNCRPD created the Committee on the Rights of Persons with Disabilities, a multi-national representative body tasked with reviewing countries' reports on their progress in implementing the UNCRPD. Article 35 requires States Parties to submit an initial report within two years of the date upon which the UNCRPD enters into force in that nation (typically 30 days after ratification) and further progress reports every three years thereafter.

Presently, the Committee faces a significant backlog of submitted reports, as

they meet only twice per year and have only been able to review a few reports at a time (United Nations Office of the High Commissioner for Human Rights, 2014). These reports typically describe, article-by-article, the progress that governments believe they are making with respect to the UNCRPD, including the extent to which they have involved people with disabilities and DPOs in national reforms and UNCRPD education efforts. Additionally, the Committee encourages NGOs and DPOs operating within each nation to submit shadow reports and responses to the national reports. These reports involve independent research and investigations, often contradicting claims made by governments in the national implementation reports.

When the Committee reviews a report, it provides an initial response and list of clarifying questions, which are returned to the government of the nation under review. The nation (as well as NGOs and DPOs) generally responds within six months for a final review by the Committee and a list of recommendations. All the documents, from the initial reports and shadow reports, to the Committee's questions and recommendations, are publically available online at the United Nations Office of the High Commission for Human Rights' website (United Nations Office of the High Commissioner for Human Rights, 2014). Although presently not organized in an ideal manner, these reports provide one of the world's largest collections of data about international disability rights and special education projects. As more reports are submitted and reviewed, the United Nations' website will certainly become the largest, most detailed database for researching international and comparative disability rights issues and monitoring outcomes of UNCRPD implementation efforts.

## **Pan-Disability UNCRPD Implementation Studies**

Several NGO's have attempted pan-disability UNCRPD implementation studies. A few examples are discussed in this section.

### **European Foundation Centre**

The European Commission, a supporting component of the European Union (EU), commissioned the European Foundation Centre (EFC) to undertake a "Study on Challenges and Good Practices in the Implementation of the UN Convention on the Rights of Persons with Disabilities" in 2009 (European Foundation Centre, 2010). In accordance with Article 35 of the UNCRPD, the EFC was employed to assist the European Union in monitoring and reporting on its implementation of the UNCRPD as well as other EU human rights projects (the Lisbon Strategy, the EU's Social Agenda, etc.). The goal of the EFC's larger study (of which the best practices study was a component) was to "analyse in detail the obligations set forth in the Convention, and in particular to gather information about the various practices related to the implementation of the Convention by the EU and its Member States" (European Foundation Centre, 2008, p. 1).

The EFC's best practices study was conducted through a qualitative questionnaire, archival document searches, and case studies, culminating in narrative descriptions of best-practices in EU member nations, organized under 13 articles from the UNCRPD (European Foundation Centre, 2010). Best-practice stories varied from awards ceremonies to legal partnerships to transportation services, in most every country in the EU. Under Article 24 (Education), the EFC highlighted:

- an assistance and resource center for teachers and families of children with

disabilities in Romania,

- an inclusive primary and preschool in London, U.K., and
- a skills training and certification program for people who are visually impaired in Hellas, Greece.

### **European Network on Independent Living**

The European Network on Independent Living (ENIL), also with sponsorship from the European Commission, conducted a pan-disability study using a mixed quantitative and qualitative, web-based questionnaire to “gauge the mood of disabled people and non-disabled people regarding the CRPD and its effectiveness...” (Jolly, 2010, p. 4). They received responses from 31 countries, both inside and outside of the EU, including countries like the United States which have not ratified the CRPD. Participants’ responses were both summarized and individually highlighted in a final report, which found majority support for the CRPD as an important tool but significant concerns about the implementation strategies employed in participating nations. Sixty-four percent of respondents self-identified as disabled; however, further data was not collected in order to disaggregate responses by disability type. Even for accessible websites, people with visual impairments and/or other disabilities may not have access or skills for using web technology.

### **The Commonwealth**

The Commonwealth Secretariat recently released a second edition of *Implementing Inclusive Education: A Commonwealth Guide to Implementing Article 24 of the UN Convention on the Rights of Persons with Disabilities* (Rieser, 2012). This book and its accompanying videos contain an extensive compilation of small,

case-study illustrations related to Article 24 of the UNCRPD and its implementation in Commonwealth nations. After describing the history and present challenges to inclusive education rights, Rieser organized the case-study examples into four categories, “Developing National Inclusion Policies” (p.114), “Inclusion at Provincial, Regional and District Level” (p. 185), “Inclusive Schools and Classrooms” (p. 227), and “Preventing Drop-out: Developing Inclusive Teaching and Learning” (p. 267). The book includes both qualitative and quantitative data, much of which was drawn from conference reports, media stories, and reports to and from UNESCO, UNICEF, the World Bank, NGOs and DPOs. Through the small case studies, Rieser shared the successes and struggles of students with varying disabilities around the globe.

The three previously mentioned reports are among the largest available international studies of CRPD implementation; however, none represents a rigorous, empirical evaluation of nations’ Convention implementation efforts, such as would be needed to develop evidence-based practices for the tool-kits and implementation projects currently undertaken by governments, NGOs, and DPOs. Likewise, the implementation reports submitted by countries to the Committee on the Rights of Persons with Disabilities also provide insight about implementation in individual nations, but they are inconsistent in their formatting, and the States Parties are not required to employ the research methods required to develop evidence-based practices (United Nations Office of the High Commissioner for Human Rights, 2014b).

### **Challenges of Surveying Participants Who Are Blind**

Ferrell (2007) declared, “..failure to recognize that inclusion and access is more than print adaptation is an example of what I call ‘visual cultural imperialism,’



where vision is viewed as the standard and all other experiences are secondary to it, and where people with ‘normal’ vision force their experiences, their perspectives, and their choices on others” (para. 10). Her observations are directly relevant to assessments, tests, and other instruments for “typical” populations which – despite popular perceptions – cannot simply be translated into braille and assumed to represent the knowledge, abilities, opinions, values, or experiences of persons with visual impairments. Therefore, while all researchers’ and advocates’ have concerns about the limitations of existing studies and reports for providing evidence-based practices for improving the lives of persons with disabilities, those in the field of visual impairments have additional cause for concern. When instruments are designed or studies are conducted without investigation of their applicability for persons with visual impairments, we must always evaluate the extent to which they are relevant to populations that include persons with visual impairments, particularly persons who are blind.

For the purposes of this study, visual impairment is defined as a broad category which includes people with limited vision as well as people who are blind. This is in keeping with the World Health Organization’s most recent revision of their *International Classification of Diseases*, which separates “visual impairment including blindness” into five categories,

- 1 – mild or no visual impairment, presenting distance acuity  $< 20/70$ ,
- 2 – moderate visual impairment, presenting distance acuity  $< 20/200$ ,
- 3 – blindness, presenting distance acuity  $< 20/400$ ,
- 4 – blindness, presenting distance acuity  $< 20/1200$ , and

- 5 – blindness, no light perception (World Health Organization, 2010b).

Even in academic publications, pan-disability studies have difficulties including participants who are blind, for reasons which I categorize as “incidence,” “access,” and “validity.”

### **Incidence**

The World Health Organization (WHO) estimated that 4.24% of the global population is visually impaired, including the .58% of the global population which is blind (World Health Organization, 2010a). The WHO also estimated that 15% of the world’s population experiences a disability (World Health Organization, 2011). Therefore, it can be estimated that blindness represents less than four percent of the population of people with disabilities.

While visual impairment is present in a significant proportion of the world’s population of people with disabilities, this percentage varies greatly from country to country, depending on factors such as sanitation, healthcare and rehabilitation services (World Health Organization, 2011). For example, the incidence of moderate/severe refractive error in high-income countries is 1.44%; in low- and middle-income countries, the incidence is 1.98%. For cataracts, the incidence in high income countries is 0.17%; in low- and middle-income countries, 0.96%. For glaucoma, the incidence in high income countries is 0.19%; in low- and middle-income countries, 0.25% (World Health Organization, 2011). Some infections and diseases, such as trachoma, are common causes of blindness but are only found in certain regions of the world and in communities without access to clean water and preventive and curative medicine (World Health Organization, 2010a).

The relatively low incidence of blindness and global incidence variations complicate any efforts of pan-disability researchers to be certain that their studies include and statistically represent people who are blind. Perhaps counter to expectations, including persons who are blind by chance in a random sample of people with disabilities may be more difficult in higher-income countries than in lower-income countries. Other factors, such as social isolation and illiteracy may lead to additional difficulties in connecting to people who are blind.

### **Access**

Persons who meet the WHO's definition of blindness typically cannot access printed text in any form; therefore, in the absence of specialized technology or an alternative literacy medium (e.g., braille or text-to-speech), they require sighted assistance to access and respond to written information, including surveys and questionnaires. For many survey instrument protocols, there are no accommodations or procedures for sighted assistance, and sighted assistance with reading and writing raises issues of the credibility of participants' responses.

Furthermore, even if researchers provide braille-transcribed versions of their instruments, not all persons who are blind have received instruction in braille. There are no comprehensive, global statistics about the education of students with disabilities; therefore, there is no way to know the literacy levels of the world population of people who are blind. UNESCO estimates that, in developing nations, only 10% of children with disabilities attend school, and the global literacy rate for adults with disabilities may be as low as three percent (one percent for women with disabilities) (United Nations Department of Public Information, 2006). Considering

the extra efforts required to access text-to-speech technology and/or provide instruction in braille, literacy levels for people who are blind should be assumed to be lower than three percent.

In order to provide all persons with disabilities equal access and opportunities to participate in pan-disability studies, researchers must build accessibility accommodations and universal design into their surveys and questionnaires (Thompson, Johnstone, & Thurlow, 2002). For persons with visual impairments, the greatest access will be achieved when researchers go beyond offering braille copies and/or providing a sighted assistant to read and record individuals' responses; we must be certain (through rigorous research practices) that questionnaires and surveys are reliable and valid for this population. Every effort should be made to enable participants to respond as independently as their peers without visual impairments. Also, as discussed in the next section, when researchers choose to adapt their instruments for accessibility (such as transcribing instruments into braille and/or providing text descriptions of images in online surveys), they must continue to be vigilant about ensuring the validity and reliability of their modified instruments for populations that include persons who are visually impaired.

### **Validity**

"We should attempt to perform a validation study whenever a test is modified or extended to a new modality" (Geisinger, 1994, p. 135).

Although Geisinger was reviewing educational and psychological tests, his proclamation is applicable to all types of instruments, including surveys and questionnaires for research purposes. Hannan (2007), in her qualitative study of

professionals' perceptions of assessment tools at specialized schools for the blind, found that 19 of 26 responding professionals reported feeling that tests used at their schools were not valid for the students being tested. Because so few instruments provide information about validity for persons who are blind, researchers should have the same concerns for the findings of pan-disability instruments as Hannan's professionals had for the findings of their scholastic assessments.

The issues of incidence and access, described previously, certainly impact the validity of any instrument or research design for making inferences about populations that include persons with visual impairment. If people who are blind are difficult to locate or include in a study, and the researcher chooses not to include them, then the results are not generalizable to *all* persons with disabilities, although they may be good explanations for populations of people with other types of disabilities. Likewise, if an instrument is not made accessible for people who are blind, then the results cannot be said to be a valid probe of their skills, needs, or opinions.

In qualitative studies, the term *dependability* is similar to reliability, and both terms are "concerned with the extent to which variation in a phenomenon can be tracked or explained consistently using the 'human instrument' across different contexts" (Teddlie & Tashakkori, 2009, p. 209). When the findings of an instrument are not consistent within a population, the instrument is said to be unreliable for that population, and instruments which are unreliable for a population are necessarily also not valid for that population (Creswell, 2012).

Geisinger (1994) discussed the impact of modifications made to instruments in order to make them more accessible. He noted that, when modifications are made, "we

do need to evaluate these modifications empirically” (p. 126) so instruments may be shown to be valid in their revised formats, measuring what they purport to measure, and scores can be equated between groups. Geisinger advised that modifications to instruments may add error to the data collected, particularly if the modifications are made locally, at the time of test administration, rather than standardized and evaluated in advance.

Construct-related validity refers to the extent to which the results of the administration of an instrument are consistent with the conceptual framework upon which the instrument was designed (Creswell, 2012). When a participant responds differently to a question because he or she is blind or has another disability, and not because of an individual difference in the construct that the instrument is intending to measure, then the question has poor construct-validity, impacting the overall validity of the instrument for reporting on the intended construct in persons who are blind/visually impaired (Geisinger, 1994).

Reid (1998; 2000) and Loeding and Greenan (1998) specifically studied issues of reliability and validity of vocational assessments for students with visual impairments. Reid (2000) found construct validity issues with the 16PF form E personality test when administered to young adults with visual impairments, indicating particular concern about items that asked participants about their leisure reading preference, their thoughts about others’ driving habits, and their preferences for observing in public spaces. She also found problems with using the tests’ normative data for “typical” participants and with optical-character recognition software solutions frequently employed to make test materials accessible. In 1998, focusing on

literacy issues in assessments of adults with visual impairments, Reid concluded, “[p]ractitioners must ... consider that the preferred reading media and working methods (including adaptive technology) used by visually impaired adults may be confounding variables” (para. 27). Additionally, Reid (1998) highlighted the connection between content validity and cultural relevance for students with visual impairments, summarizing that the common practice of transcribing instruments into braille is not sufficient for addressing all of the potential reliability and validity issues.

Alternately, Loedig and Greenan (1998) found internal consistency, high-to-moderate test-retest reliability, and accurate validity and reliability for four different vocational performance assessments when used with students with visual impairments and with students who were Deaf. These findings enabled practitioners working with students with visual impairments to feel confident in measuring their students’ vocational preparations.

Given all of the ways that the validity of an instrument for persons who are blind can be negatively impacted, rigorously validated measures for persons who are blind are understandably rare, especially outside of academic assessments. Therefore, if pan-disability international studies on the implementation of the CRPD are to be conducted, we cannot overlook the crucial steps of designing appropriate modifications for instruments which measure implementation and then validating those modified instruments.

Thompson, Johnstone, and Thurlow’s (2002) report, *Universal Design Applied to Large Scale Assessments*, provides a useful framework for approaching this modification process in a manner which improves accessibility for all participants.

The term *robust* is used to describe such instruments, when – with adaptations – a single instrument can be used to provide scores “with the same or similar meaning” (Geisinger, 1994, p. 135) for individuals with and without disabilities.

### **Quality of Life (QOL)**

After reviewing the work of the EFC, the ENIL, and Rieser, I determined that a more rigorous method for measuring implementation of the UNCRPD is needed, including a robust instrument suitable for pan-disability research in populations including persons who are blind. Research into the construct *quality of life* provides a promising path towards such an instrument.

### **Quality of Life and International Disability Rights**

Quality of life (QOL) has many different meanings depending upon the context in which it is used. Most research into the experiences of people with disabilities is certainly connected to the most common understanding of “quality of life,” meaning that some people experience barriers to QOL while others have those barriers removed. Ideally, advocates want to do things to improve QOL as much as possible. In the United Kingdom, a chronic problem of harassment and abuse of people with disabilities definitely impacted QOL negatively (Equality and Human Rights Commission, 2012), while the World Bank’s work in the Middle East and North Africa will hopefully remove obstacles for people seeking to live fuller lives of greater quality (Kaur, 2010).

A related, more academic definition or approach to “quality of life” considers the term QOL as a theoretical construct, comprised of many component constructs, primarily subjective but also including objective, measurable factors in an individuals’



life. For many QOL researchers, QOL is central to understanding, evaluating, and improving the actual impacts of any intervention or service as experienced by participants. QOL is a construct that can be used in research designs to track and monitor the improvement in people's lives over time. QOL can also be used as a measure of success. For example, the World Health Organization might wish to know if their integrated approach to increasing employment for persons with disabilities leads to increased QOL in a particular community (Kaur, 2010). If they find that QOL does not improve, they may try another approach; if it does improve, then perhaps they will use the same approach again in another community.

To understand how QOL connects with research designs and evaluation and thus with international disability rights interventions and monitoring of programs like the UNCRPD, it is useful to describe how different researchers have approached QOL.

### **International Association for the Scientific Study of Intellectual Disability's SIRG-QOL**

The International Association for the Scientific Study of Intellectual Disability (IASSID), founded in 1996, includes a Special Interest Research Group on Quality of Life (SIRG-QOL). These scholars and practitioners have chosen a uniquely human-rights-oriented approach to QOL which is best illustrated by describing their criteria and conceptualization of research on this topic (Schalock, 2005).

**IASSID's criteria for QOL research.** IASSID states that QOL should be studied as a multifaceted concept (Schalock & Verdugo, 2002). Researchers should study QOL in multiple systems (such as Bronfenbrenner's [1979] ecological systems)) and should use QOL research to promote change and improvement in

participants' lives. Researchers must also use multi-method approaches to QOL – neither solely qualitative nor solely quantitative.

**Universality of QOL construct.** IASSID asserts that QOL is comprised of the same factors for all people – whether the Maasai of Africa or the Civil Service employees in India. Certainly these vary in importance among cultures, but the single construct of QOL is applicable to everyone. This construct is comprised of both subjective and objective elements and has implications at the micro-, meso-, and macro-system levels (described by Bronfenbrenner, [1979]).

**Eight domains.** While IASSID is open to researchers using any theoretical model of QOL as long as it fully encompasses the concept, they recommend the following eight-domain model:

- Emotional well-being
- Interpersonal relationships
- Material well-being
- Personal development
- Physical well-being
- Social inclusion
- Self-determination
- Rights

In 2012, Verdugo, Navas, Gómez, & Schalock further connected QOL and the UNCRPD by developing a table outlining the relationship between a (revised) three factor structure of QOL, the above-mentioned, eight international QOL domains, and the 34 articles which comprise the main objectives of the UNCRPD. They expressed

the belief that the QOL framework, based on Schalock and Keith's 1993 QOL.Q and since further developed and revised, is a step towards allowing "policy makers, service providers, and the population in general to understand and evaluate how the implementation of these [UNCRPD] rights are translated into improved human functioning and personal-outcomes reflective of one's human rights" (Verdugo et al., 2012, p. 1039). Verdugo et al. believed the QOL framework to be a crucial tool for turning political ideas into evidence-based practices.

Additionally, Jenaro et al. (2005) validated the emic and etic structure of this eight domain model across several cultural groups. (Emic properties are those aspects which can be identified with a particularly cultural group; thus people within groups tend to score similarly on emic measures and people between groups tend to score differently. Etic properties are not related to cultural groups and thus tend not to display statistically different patterns between cultures).

IASSID recommends that instruments designed to measure QOL contain indicators for each of the eight domains at each of Bronfenbrenner's three ecological systems levels (Schalock, 2005). Micro-system indicators are typically recorded in personal appraisals, meso-system indicators are often functional assessments, and macro-system indicators are usually national-level, social measures (such as whether or not certain protections are granted under the law).

### **Health-Related Quality of Life**

As an alternative to the construct of QOL researched and advocated by IASSID's SIRG-QOL, many researchers approach QOL from a medical or health-related standpoint. Schalock and Verdugo (2002) refer to this as HR-QOL and explain

that this conceptualization of QOL is more often used in etiological research, evaluations of social and health programs, resource allocation, and clinical decision-making.

The WHO Division of Mental Health and Prevention of Substance Abuse published an instrument (the WHO-QOL) to measure this type of QOL in 1995. Their instrument is based upon the WHO's definition of health, "a state of complete physical, mental, and emotional well-being, not simply the absence of disease," and their definition of QOL is "an individual's perception of his/her position in life in the context of culture and values and with recognition of [goals, standards, and obstacles]" (World Health Organization Division of Mental Health and Prevention of Substance Abuse, 1997). Their theoretical model of QOL contains six domains: physical, psychological, level of independence, social relations, environment, and spirituality, and the WHO-QOL's indicators are primarily subjective and at the micro-system and meso-system levels (without reference to external indicators such as social protections and rights).

### **Implications of QOL for International Disability Rights**

Both the IASSID's human-rights-oriented model of QOL and the WHO's health-oriented model of QOL have great potential for resolving some of the implementation and monitoring challenges related to international disability rights. In special education and education in general in the United States, we recognize that accountability is very important – policymakers and funders will only continue to support work that they believe is successful. Likewise, the Committee which reviews States Parties' reports on UNCRPD implementation (a requirement of Article 35)

wants to know that countries are making progress on their intervention efforts to improve the rights of persons with disabilities, and investors like the World Bank want to know that they are putting their money towards cost-effective development programs (Legovini, 2010).

By developing and validating QOL instruments (most commonly surveys and questionnaires), researchers can become active participants in the evaluation of interventions and strategies, helping to reduce inefficiencies and identify and promote best practices. Karr (2011) noted that the CRPD does not clearly define how to measure its own implementation but that QOL provides a well-matched tool for this task.

Additionally, QOL (particularly as conceptualized by the IASSID) is well suited for engaging people with disabilities in action research. Outside researchers can struggle with understanding the lived experience of a culture or community, but QOL investigations permit people with disabilities to be involved in and even to design and conduct their own implementation and monitoring strategies. Thus, DPO's such as Disability Rights International can be actively engaged with monitoring and evaluation. Even newly formed, struggling DPO's like those supported by the UK's Department for International Development and described by Mwendwa, Murangira, and Lang (2010) in Uganda can develop tools and techniques for self-evaluation to monitor and improve their own efficacy.

No policy changes are needed to begin implementing QOL as a tool for monitoring and evaluation in the international disability rights field. Researchers do need to continue to explore the multi-faceted construct of QOL and ensure that well

validated instruments are available that can be used with diverse populations and measure important differences and changes over time. Work should be done to consider the relevance (if any) of separating health-related QOL from a broader, disability-oriented model. Ideally, one instrument or set of instruments could be used by all types of researchers and data could be shared for multiple purposes.

The following sections discuss instruments developed from both IASSID's theories of QOL and health-related QOL theories.

### **Schalock & Keith/IASSID QOL Instruments**

As previously discussed, the quality of life (QOL) framework and instruments researched and developed by IASSID and Schalock and Keith (1993, Keith & Schalock, 1995) have not only been connected with the UNCRPD but have also been validated for a range of disabilities, languages, and cultures. With additional research to determine and validate appropriate adaptations for persons who are blind or visually impaired, these existing QOL instruments (one for adults, one for students) have the potential to serve as powerful tools in the development of evidence-based practices for implementation of the UNCRPD.

Schalock and Keith published the Quality of Life Questionnaire (QOL.Q) in 1993 "to meet the need for an instrument to assess QOL in persons with [intellectual disabilities] and developmental disabilities" (p. 4). Using existing research, they developed the construct of QOL around four indicators, each of which is meant to be measured from the perspective of the individual:

1. Empowerment/Independence
2. Competence/Productivity

3. Social Belonging/Community Integration
4. Satisfaction.

Schalock and Keith intended their 1993 QOL.Q instrument to have applications for assessment of individuals' needs, program evaluation, and research. Importantly, they state several basic assumptions about their interpretation of the QOL construct:

1. QOL is subjective; it cannot be measured separately from the perceptions of the individual.
2. QOL is not differently constructed for persons with or without disabilities.
3. QOL, a “social phenomenon” (p. 8), depends significantly upon interactions with others.
4. QOL results from a person having his/her needs fulfilled and also from being able to accomplish basic roles in his/her community.
5. QOL can be assessed in a standardized way, either through subjective self-reporting or through ratings from persons who are well acquainted with the participant.

Following upon their work on the QOL.Q, in 1995, Keith and Schalock published a second instrument, the Quality of Student Life Questionnaire (QSLQ), for evaluating the same construct of QOL in students with and without disabilities from junior high through college age. For this instrument, the validated sub-scales were:

- Satisfaction
- Well-being
- Social Belonging, and

- Empowerment/Control.

In 2011, Karr published a study which used a shortened version of the QOL.Q to study QOL (and other constructs) and their usefulness for informing the UNCRPD.

She concluded,

... information must continue to be gathered regarding the current QOL and circumstances of persons with disabilities at individual, legislative, policy, program, and social-attitudinal levels for systems-level change...[I]nformation and the existence of the UNCRPD alone are not enough; people with disabilities must be provided with trainings that support the development of SD [self-determination] and advocacy skills to improve QOL. (Karr, 2011, p. 12)

**Validity for other groups.** Another major strength of Schalock and Keith's (1993) QOL framework is its relative robustness for use in many contexts. Caballo, Crespo, Jenaro, Verdugo, and Martinez (2005) validated a Spanish version of the QOL.Q for use both with persons with physical disabilities and persons with intellectual disabilities. Jenaro et al. (2005) replicated the findings of Schalock et al. (2005), demonstrating cross-cultural validity (over the two studies) in Italy, France, Belgium, Poland, Latin America, Spain, China, Canada, and the United States.

**QOL.Q studies with participants who are visually impaired.** Two studies have used versions of Schalock and Keith's (1993) QOL.Q with participants who are blind; however, neither study provides a rigorous demonstration of validity of the instrument for populations which include people who are blind.

Rimmerman and Morgenstern (2003) used the QOL.Q in their study of the QOL of adults with visual impairment in extended-employment programs in Israel, finding that QOL was higher in participants who had spent more time in their program and in participants who expressed greater acceptance of their visual impairments.



However, the authors provided no discussion of the validity of the QOL.Q for this population.

Verdugo, Prieto, Caballo, and Peláez (2005) studied the use of the QOL.Q, translated into Spanish and orally administered to persons with visual impairment in Castilla y León, Spain. They found inconsistencies in the factor structure of the resulting data and therefore proposed a new instrument (with 24 instead of 40 items) and a new factor structure for describing three (instead of four) subscales. Verdugo et al.'s claim that "the hypothesis of the new model is appropriate for use with visual disability" (2005, p. 30) is unconvincing because they attempted to validate many population differences (culture, language, and disability type) at once; thus, they could not demonstrate which factors necessitated the changes in the instrument. Additionally, they did not provide data on whether their participants were blind or had more moderate forms of visual impairment.

**Weaknesses of the QOL.Q.** Based on the limited literature on the use of the QOL.Q with persons with visual impairments (and the absence of research specifically on persons who are blind), further investigation is necessary to more precisely understand the validity of the QOL.Q for persons who are blind. Additionally, no studies have looked at the validity of the QOL.Q's student version, the Quality of Student Life Questionnaire (QSLQ), for students who are blind. This instrument has great potential for helping to monitor the international implementation of Article 24 (on education) of the UNCRPD and contributing data to the international discussions of the merits of inclusive education.

## Health-Related QOL Instruments

Assumptions about the social construction of disability differentiate IASSID's QOL construct from other approaches to QOL, particularly those used in medicine. Thus, the QOL.Q is fundamentally different from health-related QOL instruments. For example, Rahi, Tadić, Keeley, and Lewando-Hundt (2011) studied *vision-related quality of life* in children and young people. Vision-related QOL is an aspect of health-related QOL which is concerned with understanding the impacts on a person's life that are the result of an optic medical condition. Although Rahi et al. expressed that health-related QOL is increasingly interpreted to incorporate subjective aspects, their (and the medical community's) construct of QOL is fundamentally different from IASSID's, which has no medical aspects and does not differentiate by disability or the presence/absence of a medical condition.

The WHO published an instrument, the WHOQOL, to measure health-related QOL in 1997. Their instrument is based upon their definition of health, "a state of complete physical, mental, and emotional well-being, not simply the absence of disease," and their definition of QOL, "an individual's perception of his/her position in life in the context of culture and values and with recognition of [goals, standards, and obstacles]" (World Health Organization Division of Mental Health and Prevention of Substance Abuse, 1997, p. 1). The WHOQOL's 100-question version (WHOQOL-100) contains five domains: *physical health*, *psychological*, *level of independence*, *social relationships*, and *environment*, while their more recent, 26-question version (WHOQOL-BREF) condenses the domains to *physical health*, *psychological*, *level of independence*, and *environment* (World Health Organization Division of Mental Health

and Prevention of Substance Abuse, 1998). The WHOQOL's indicators are primarily subjective and at the micro-system and meso-system levels (without reference to external indicators such as social protections and rights). Notably, the World Health Organization developed a detailed process for constructing their WHOQOL, conducting many focus groups in a variety of cultural settings to ensure that the voices of participants (service providers and persons with disabilities) were included in the questionnaire design. However, the WHO did not offer users of the WHOQOL any information about validity of their instruments with populations that include persons who are visually impaired.

### **Developing a Valid QOL Instrument for Persons Who Are Blind**

Given the limitations and unknown validity and reliability of the previously discussed, existing QOL instruments for populations including persons with visual impairments, steps should be taken either to validate and/or improve existing instruments or to develop new measuring tools. In the interest of advancing a single tool, perhaps with multiple versions, which will effectively measure QOL for diverse populations, steps must also be taken to address concerns about incidence, access, and validity relevant to quantitative studies involving persons with visual impairment (see previous discussion under heading "Challenges of Surveying Blind Participants").

In determining the validity and reliability of instruments for populations including persons with visual impairments, researchers have used a variety of statistical and non-statistical techniques. Reid (2000) physically examined the accessibility characteristics of personality inventories. Using a checklist, she reported on the acceptability of tests' normative data, and the effectiveness of low-vision

devices, closed-circuit televisions, and optical-character recognition tools when applied to each test. Loeding and Greenan (1998) used inferential statistics, including Cochran's  $\alpha$  (for internal consistency of self- and teacher-ratings and open-ended items), the Kuder-Richardson 20 coefficient (for internal consistency of multiple-choice items), and Pearson's  $r$  for test-retest reliability and construct validity. Geisinger (1994) recommended factor-analysis (for construct-related validity) as well as differential-item functioning for assessing the equivalence of questions on two versions of an instrument.

For the majority of the statistical tests of validity mentioned above, except tests of content validity, investigators made use of existing theoretical frameworks and previously validated instruments to compare/contrast with the data they collected. No such framework exists, to my knowledge, to describe the subjective, human-rights-related QOL as experienced by persons with visual impairment. Therefore, such a framework must be developed before judgments can be made about the construct validity of any existing or newly developed QOL instrument.

### **Summary, Implications, and Discussion**

This literature review began with a focus on the UNCRRPD and the need for instruments to evaluate nations' implementation efforts in order to help determine evidence-based practices. Once researchers present rigorously validated, robust tools for determining the effectiveness of various implementation efforts, governments, NGOs, and DPOs can measure the effectiveness of their UNCRRPD implementation toolkits and national projects, sorting out which educational, legal, and social changes produce the greatest benefits in the lives of persons with disabilities. The United

Nations Committee on the Rights of Persons with Disabilities will also benefit from validated measurement tools to aid in their evaluation of nations' UNCRPD implementation efforts.

A few studies and reports (European Foundation Centre, 2008; Jolly, 2010; Rieser, 2012) have attempted to summarize effective practices in UNCRPD implementation, but none have employed the rigorous scientific methods necessary to demonstrate evidence-based practices. Schalock and Keith's development of the QOL.Q and QSLQ (Keith & Schalock, 1995; Schalock & Keith, 1993) have been repeatedly demonstrated as reliable and valid measures of QOL for a variety of populations, and recent research (Karr, 2011; Verdugo et al., 2012) supports the use of this QOL framework for evaluating the implementation of the CRPD. The World Health Organization has also put forth a QOL instrument and an instrument-development process with strengths for international data collection (World Health Organization Division of Mental Health and Prevention of Substance Abuse, 1997).

For many reasons, people who are blind are prone to be excluded or inappropriately assessed by researchers and research instruments; therefore, there is a pressing need for a UNCRPD evaluation instrument robust enough to measure (with validity and reliability) the impact of UNCRPD-related reforms on populations that include persons who are blind. Recognizing that a theoretical model of QOL for students with visual impairment is necessary before it can be determined if any instruments are valid for studying the impact of the UNCRPD, the next, logical steps are to collect qualitative data about the essence of QOL as experienced by students who are blind and to suggest such a framework.

An investigation of the essence of QOL for students who are blind will also provide a valuable model to be used by leaders and researchers in special education, disability studies, and policy development. Such an investigation has the potential to provide insights as to differences in the way “quality of life” is understood by students who are blind and who attend residential/non-residential schools or who have other demographic differences. Ultimately, including students who are blind and visually impaired in the process of developing any model of QOL is in line with the core principles identified by QOL researchers and will both affirm the “nothing about us without us” mandate from the UNCRPD and enrich our understanding of students’ perceptions and understandings of QOL.

### **CHAPTER III**

#### **METHODOLOGY**

This study was undertaken in order to develop a theoretical foundation which can be used to investigate the validity of existing QOL instruments such as the WHOQOL, QOL.Q, and QSLQ and to improve their usefulness for surveying populations that include young adults who are blind. Using qualitative methods, I provided evidence for a model of the essence of QOL as understood by young adults who are blind. The constructs and indicators within this model can be compared and contrasted with the constructs in the existing QOL frameworks, and statistical construct validation investigation can be performed using existing, revised, and/or newly developed instruments. Ultimately, a validated, reliable instrument which enables the study of QOL in populations including persons with visual impairments will empower program evaluation and participant-action research into QOL of students and adults in various educational placements and life circumstances within diverse situations around the globe.

With a validated, improved QOL instrument, human rights monitors will be able to more fully study countries' implementation of the UNCRPD, and strategies for enhancing QOL and improving human rights may be developed and tested. Research-based practices will inform international decision-makers and support more efficient funding of non-governmental organizations' (NGOs) and disabled-persons organizations' (DPOs) projects.

#### **Paradigm: Qualitative Research**

Historically, QOL has been studied using quantitative methods. Schalock and

Verdugo (2002) ascribe this preference of methodologies to the positivist nature of research in the fields of medicine and psychology, which seeks to use statistical analysis to draw conclusions about populations. Surveys have by far been the most popular quantitative tools in QOL studies (Schalock & Verdugo, 2002), and among the most notable QOL survey instruments are Schalock and Keith's Quality of Life Questionnaire (QOL.Q) (1993) and the World Health Organization's WHOQOL (1997).

Quantitative studies and survey instruments designed to measure QOL for the evaluation of national human rights interventions, such as those connected to the UNCRPD, must be versatile and must provide data that is useful for both pan-disability studies and for monitoring the progress of the rights of particular groups of people. Unfortunately, although QOL survey instruments are being used in pan-disability studies, existing QOL survey research is lagging in its ability to provide valid information with respect to people with visual impairments.

### **Qualitative Approaches to Quality of Life**

My investigation was exploratory in nature, seeking to generate theory where none exists, and was therefore not suited to quantitative investigation. The qualitative paradigm, which offers more flexibility for smaller sample sizes and emphasizes deeper understanding of individual participants' experiences, is a better fit for the task of discovering how QOL is experienced by young adults who are blind. Schalock and Verdugo (2002) recognized that qualitative and mixed methods approaches are becoming increasingly more common in QOL research, and the IASSID emphasized that all QOL researchers should be considering research designs that incorporate



multiple methods and perspectives (Schalock, 2005).

In general, qualitative studies are aligned with one or more of these categories: ethnography, narrative, case study, grounded theory, and phenomenology (Creswell, 2012). These categories often overlap, as with ethnographies frequently expressed as narratives and case studies occurring within phenomenological analyses.

Qualitative research is especially relevant to disability-related research because it provides greater space for contributions from participants. Many qualitative researchers engage in “action research” – projects designed to influence change, and “participatory action research” – studies which intentionally engage participants as co-researchers. The IASSID strongly urges QOL researchers to include individuals with disabilities and their families in the design, implementation, and evaluation of all QOL studies (Schalock, 2005). QOL research is conducted with the intention of improving QOL for marginalized people by measuring and monitoring trends in people’s lived experiences; therefore participatory, qualitative studies are well suited for investigations related to QOL.

Qualitative researchers generally do not seek to uncover objective truths and facts, as is often the case with quantitative research. Because qualitative data is not numeric, researchers are not concerned with statistical validity and reliability. However, qualitative researchers do seek to produce research of high quality and rigorous standards.

Due to the precedence of quantitative methods in most fields, many of the standards for qualitative research are aligned with but not identical to traditional notions of validity and reliability in quantitative research (Elliott, Fischer, & Rennie,

1999). Lincoln and Guba (1985) suggested that instead of internal validity (the extent to which a quantitative researcher is measuring what he or she intends to measure), qualitative researchers should be concerned with authenticity and trustworthiness. Readers of qualitative research should be given enough information to feel confident that the researcher has provided an honest account of his/her encounter with the participants, and the researcher should be upfront about his/her own preconceptions and biases. Likewise, instead of being concerned with statistical reliability, qualitative researchers seek to produce research which is highly dependable; thus, another investigator could have reasonably come to similar conclusions. Where quantitative researchers are concerned with external validity, qualitative researchers provide rich descriptions so that their future readers can ascertain “transferability” – the extent to which the findings of a qualitative study may or may not be transferable to other persons or circumstances.

More recently, qualitative researchers have proposed standards of quality which are not as strictly aligned to traditional notions of validity and reliability. Yardley (2008) suggested four principles for evaluating qualitative research:

- “sensitivity to context
- commitment and rigor
- transparency and coherence, and
- impact and importance” (Hefferon & Gil-Rodriguez, 2011, p. 758).

Smith, Flowers, and Larkin (2009) suggest that *sensitivity to context* can be addressed through consideration of existing literature, sustained engagement with participants, well planned data collection, “interactional” (p. 180) data analysis, and

evidence (such as verbatim quotes) from participants to support written conclusions. *Commitment and rigor* are demonstrated through attentiveness to participants, quality data collection, and thorough analyses with conclusions that fairly and proportionally represent the participants. For qualitative studies to adhere to the *transparency and coherence* principle, researchers must clearly describe their research process including participant selection, data collection, and analysis. Finally, impact and importance must be demonstrated by the provision of research and conclusions which are “interesting, important, or useful” (Smith et al., 2009, p. 183).

Elliott, Fischer, & Rennie (1999) proposed an alternate set of quality indicators for qualitative research, separating those factors which were applicable to both quantitative and qualitative research from the principles that were applicable only to qualitative research. Their guidelines relevant to qualitative research included:

- “owning one’s perspective
- situating the sample
- grounding in examples
- providing credibility checks
- coherence
- accomplishing general vs. specific research tasks, and
- resonating with readers” (Elliott et al., 1999, p. 220).

These different methods of establishing “quality” in qualitative studies all emphasize the subjective, interpretive nature of qualitative research. Unlike quantitative research which seeks to establish objective measurements and to uncover “truth”, qualitative research generally investigates experiences and understandings

which will be unique to the participants. Although qualitative results are not always transferable to other populations, over time and multiple studies, they shed light on different aspects of human experience which often cannot be quantitatively measured. Also, as with my investigation, qualitative studies can lay the groundwork for theories and hypotheses that can later be tested using quantitative methods.

### **Method: Phenomenological, Thematic Analysis**

First considered by Husserl, phenomenology is a philosophical approach and deals with questions of meaning-making and the essence of experience, seeking to uncover a deep understanding of participants' lived experiences (Smith et al., 2009). Husserl sought to better understand the "essence of experience" and, thus, to better understand human consciousness and perhaps even to transcend the researcher perspective and to gain insight into a purer vision of the participant's actual experience (Smith et al., 2009). Other philosophers – Heidegger, Merleau Ponty, and Sartre – refined phenomenology by considering the multiple layers involved in interpretation. In a researcher's interview, the researcher is interpreting the story as told by the participant who is interpreting the story from his/her own memory. Transcription adds another layer of interpretation. Thus, any final analysis is tinged multiple times with the pre-conceptions and thought structures of these various interpreters. Phenomenological researchers should try as much as possible to "bracket" their own preconceptions in order to get closer to the actual experience of the participant.

QOL is integrally connected with "lived experience;" thus, a phenomenological approach to investigating quality of life allowed me to deeply consider the experiences of a limited number of participants and look for themes and

connections within and among each participant's story.

### **Research Questions**

Primary question: What is the essence of "quality of life" as experienced by young adult students who are blind and enrolled in post-secondary educational programs?

Secondary questions:

1. How is the essence of quality of life as experienced by young adult students who are blind influenced by the student's primary and secondary school experiences?
2. To what extent is the essence of quality of life experienced by young adult students who are blind similar to/different from the theoretical models, constructs, and indicators of quality of life present in existing quality of life instruments and research?

The primary question addresses the phenomenological inquiry into the experience of QOL, which has been the objective of my research. The first secondary question targets additional insights which can be drawn from the qualitative data and which will contribute to a better understanding of the educational experiences of young adults with visual impairments. Finally, the second secondary question furthers my pursuit of a validated QOL instrument for persons who are blind or visually impaired by comparing and contrasting themes derived from the qualitative data with QOL indicators, constructs, and models that are currently in use with diverse populations containing persons with disabilities.

### **Data Sources**

I derived the data for this study from eighteen, semi-structured, face-to-face interviews, involving six young adults who are blind. The analysis was drawn from transcripts of the interviews and a researcher's journal. I adopted the three-interview structure recommended by Seidman (2013) for phenomenological interviewing, where the first interview emphasizes the participant's life history, the second interview focuses on details of the relevant experiences, and the final interview reflects upon meanings made by the participant relevant to his/her experiences. Interviews followed pre-written, semi-structured protocols based upon the protocols used by Poston, Turnbull, Park, Mannan, Marquis, and Wang (2003) in their constant-comparative study of *family quality of life* and by Borglin, Edberg, and Hallberg (2005) in their phenomenological study of QOL as experienced by older people.

### **Participants and Sampling**

Based upon the phenomenological nature of my research questions, I selected a small, homogenous sample of people with a shared experience. Larger samples are especially time consuming and difficult to analyze in sufficient depth; therefore, I identified six participants, reserving the possibility of adding further participants to achieve a saturation of themes during the analysis; however, I found that additional participants were not necessary (Creswell, 2012).

To increase homogeneity in my sampling, I narrowed the larger population of persons with visual impairments to the more consistent population of young adult students (ages 18-25) who are blind and who are attending post-secondary programs in the United States (college, vocational school, work-study programs, transition

programs, etc.). Participants had to be willing to communicate about their experiences through spoken English (as determined by the person who referred them as a potential participant or as determined by me during a pre-interview telephone call), and I was open to including participants with additional disabilities.

The World Health Organization's most recent revision of their *International Classification of Diseases* defined visual impairment as including mild and moderate visual impairment and three categories of blindness. For the proposed study, participants had acuities in the lowest two categories of blindness:

- blindness, presenting distance acuity less than 20/1200, or
- blindness, no light perception (World Health Organization, 2010b).

This purposeful sample was gathered through my professional network of connections with state schools for the blind, state universities, state rehabilitation agencies, and national organizations for young adults who are blind or visually impaired. All participants were from the southwestern United States.

Of the six identified participants, three were male and three were female. All were between the ages of 18 and 22. Three were university students enrolled in bachelor's degree programs, one was in a transition program that combined courses at a school for the blind and a community college, one was in a transition program that combined courses at a rehabilitation center and a community college, and one was in a transition program that combined courses at a school for the blind with courses at a rehabilitation center. Table 3.1 provides demographic information about the participants. Additional details about participants are provided in Chapter 4.

Table 3.1

*Demographic Characteristics of Participants*

Parameter	Alex	Brianne	Darik	Janessa	Martin	Tess
Age	20	19	22	20	19	22
Gender	male	female	male	female	male	female
Ethnicity	Caucasian	Caucasian	African-American	African-American	Hispanic-American	Caucasian
Origin of visual impairment	bilateral retino-blastoma	optic atrophy	bilateral retino-blastoma	bilateral retino-blastoma	medical treatment during infancy	an-ophthalmia, micro-ophthalmia
K-12 experience	public schools	public schools	public schools	public schools	public schools through 8 <sup>th</sup> grade; high school at school for the blind, including courses at public school	public schools
post-secondary enrollment at time of interview	university	transition program at school for the blind including courses at rehabilitation center	university	transition program at school for the blind including courses at rehabilitation center and community college	transition program at school for the blind including courses at community college	university

Participants were provided with a description of the study and all the documentation necessary so that I could obtain informed consent according to my university's Internal Review Board (see Appendix B for approval letter from the Internal Review Board). In addition, participants each received \$50 in gift cards over the course of the three interviews to thank them for their time and assistance with the research. Participants all granted permission for me to contact them following the



initial interviews for follow-up interviews and member-checking to improve the quality of my thematic analysis.

### **Interviews**

Within semi-structured interviews, I was able to elicit participants' personal accounts, experiences, and reflections on QOL. According to the American Printing House for the Blind's 2013 survey of students with visual impairment, only 8.58% of U.S. students with visual impairments used braille as their primary reading method. Storytelling and conversation in the oral medium is perhaps a more commonly accessible communication mode for persons who are blind, and by collecting data through interviews I avoided any complications of communicating through braille or technologies that may not have been equally well understood by people with visual impairments in this study or replication studies (Thompson et al., 2002).

Credibility checks, through consultation with participants and through collaboration with a team of professionals, promoted the trustworthiness of the findings (Elliott et al., 1999). In the study, all data collection occurred through interviews and my personal reflections in a research journal, and the quality of the study, including the credibility of the conclusions, was supported by rigorous consideration of the aforementioned quality indicators from Yardley (2008) and Elliott, Fischer, and Rennie (1999).

### **Data Collection**

My participants were recruited through my professional network of connections with state schools for the blind, state universities, state rehabilitation agencies, and national organizations for young adults who are blind or visually

impaired. An informational letter describing the project was sent to colleagues and social media networks with the request that they assist me in identifying and contacting potential participants.

I purposefully selected six participants who met my previously defined criteria. During the data analysis, the characteristics of the participants enabled consideration of differences in participants' experiences based upon the dimensions of gender and present educational setting.

### **Interviews**

Each participant was interviewed three times in face-to-face interviews, averaging approximately 72 minutes (maximum 92 minutes, minimum 49 minutes). As suggested by Smith, Flowers, and Larkin (2009), interview locations were chosen in advance by the participants and ranged from participants' apartments to outdoor cafés to meeting areas and offices on school campuses.

The interview protocols were reviewed by colleagues who are blind and who work with young adults with visual impairments in a rehabilitation setting, and revisions were made based upon their feedback. See Appendix A for protocols for the three interviews. During the interviews, I asked open-ended questions and listened attentively to participants' responses, taking notes as reminders for follow-up questions. Between the first and second interviews and between the second and third interviews for each participant, I listened to the audio-recordings of the participant's prior interview, enabling me to integrate follow-up questions into the second and third interviews. I consciously worked to minimize my own voice in the conversations, as I prompted participants to describe their understandings and experiences related to

QOL; however, interviews varied in the extent to which participants required prompting.

Each interview was recorded and transcribed to produce a semantic record of the original interview (conventional spelling of the spoken words along with descriptions of pauses and non-grammatical utterances). This process began shortly after the initial interviews, such that I was engaged in transcribing, reviewing and making notes in between scheduling and conducting additional interviews. Transcription software and equipment combined with speech-to-text dictation software aided in the transcription task.

During the analysis, I incorporated notes from my researcher's journal and referenced important documents from my experiences as a Teacher of Students with Visual Impairments (such as the Expanded Core Curriculum for Students with Visual Impairments [American Foundation for the Blind, 2014]); however the interview transcripts served as the dominant and most significant data source for this study.

### **Data Analysis**

I employed MAXQDA qualitative data analysis software throughout the analysis of the interview transcripts. The nature of the data – with multiple and diverse opinions and experiences per participant – suggested a cross-case, thematic analytical approach, within which I considered important concepts arising from the entire collection of ideas and stories. In determining particular procedures for the analysis, I was influenced by Glaser's (1965) Constant Comparative Method for generating theory from qualitative data, including the coding of incidents within the data into potential categories (*codes*), integrating categories by comparing incidents and codes,

and restricting the theory by developing thematic groupings of codes (*themes*). Likewise, Creswell (2012) suggested qualitative analysis should begin with a preliminary exploration of the data, followed by a coding process and the development, description, and interrelating of themes.

I read through each transcript a minimum of three times during and after the transcribing process, noting potential themes in my researcher's journal. Using MAXQDA, I assigned codes to segments of the transcript and tracked these codes in the software throughout the analysis of each interview, revising definitions of codes and incorporating new codes as necessary based upon the data. I engaged in constant comparison of codes, regularly returning to previously analyzed interview segments to apply new codes or revise existing codes. Following a rigorous coding of all transcripts (identifying over 2,300 significant text segments), I applied the constant comparative approach across codes, reducing the number of codes through an iterative process of combining similar codes, deleting irrelevant or duplicate codes, and re-defining codes to better represent patterns in the texts. The MAXQDA software's frequency counts and code co-occurrence tools aided in determining whether or not themes and categories under consideration were well supported by the data. The software also preserved the connections between codes and text segments, crucial for the audit trail presented in Chapter 4.

Through this process, I identified a thematic framework which aligned with important patterns I perceived. The resulting, delimited themes arose both from among the particular codes and from across the interviews as a whole (as supported by notes in my researcher's journal and memos in the MAXQDA software system).

Participants were provided with electronic copies of their interview transcripts as well as a list of major themes and sub-themes for review and feedback. I stored the electronic recordings of the interviews as well as the document files for the transcripts on an external hard drive and a lap-top computer. Hardcopies of the transcripts were stored in a binder.

### **Ensuring Trustworthiness**

As advised by Smith, Flowers, and Larkin (2009), and as recommended by Hefferon and Gil-Rodriguez (2011) in their discussions of phenomenological methods, I protected the quality and trustworthiness of the proposed study by adhering to the quality indicators proposed by Yardley (2008) and Elliott, Fischer, and Rennie (1999).

### **Owning one's Perspective**

Elliott, Fischer, and Rennie (1999) call for authors to clearly describe their theoretical orientations and predictions before and during the analysis. I discussed my perspectives with my committee, wrote about them in a researcher's journal, and describe them for the readers in my introduction, analysis and conclusions.

### **Situating the Sample**

Additionally, I have described the participant sample in detail for the readers of my analysis and conclusions to form judgments about the relevance and transferability of my findings (Elliott et al., 1999), see Table 3.1 for demographic information and Chapter 4 for narrative descriptions of participants. I have taken care to protect the confidentiality of my participants by using pseudonyms and avoiding sharing personally identifiable information.

### **Grounding in Examples**

My final written analysis and conclusions include verbatim quotations from the transcribed interviews to illustrate my analysis and to support the authenticity of my findings. This will aid readers in judging the quality of my analysis and in considering plausible alternative interpretations (Elliott et al., 1999).

### **Providing Credibility Checks**

Two techniques have been used to support the credibility of my data collection, analysis, and interpretations. First, participants were consulted during each interview and during the analysis to check that my understandings were in line with their actual feelings and experiences. Additionally, additional researchers experienced in qualitative analyses were asked to review my analyses for “discrepancies, overstatements, or errors” (Elliott et al., 1999, p. 222).

### **Transparency and Coherence**

Coherence involves the extent to which the volume of diverse data is integrated into a comprehensible representation while maintaining the subtleties of the individual participants and their experiences (Elliott et al., 1999). Thus, in my study, themes that arose from the data were considered in relation to one another so as to demonstrate connections and relationships among the diverse experiences and perceptions of the participants. This process is in line with my goal of developing a theory of the construct of QOL as experienced by persons with visual impairments. Coherent analysis and conclusions are crucial so that future studies may build upon and enhance my emerging theory.

At the same time, this coherent analysis clearly preserves my data collection

and analysis processes for review by others. This transparency has been enhanced by including figures and tables in my written report to convey the details of the investigation (Smith et al., 2009).

### **Accomplishing General vs. Specific Research Tasks**

I expressed a goal of developing a theory of QOL for persons with visual impairment; however, my research questions convey the reality that this study is only the beginning of that larger, theory-development process. Therefore, the aim of the study has been the specific task of better understanding the more specific experience of QOL by my young adult participants who are blind. My investigation focused on the specific cases of my participants and their experiences, acknowledging the limitations of this initial study for drawing conclusions about the larger population of persons with visual impairments (Elliott et al., 1999).

### **Resonating with Readers**

My final written analysis provides readers with meaningful, relevant insight into the experience of QOL for young adults with visual impairments. I have made efforts to write both accessibly and meaningfully in order to inform both the field of visual impairments and those who are researching QOL. Multiple drafts and careful editing, as well as feedback from participants, have helped in the crafting of analyses and conclusions are both informative and impactful (Elliott et al., 1999).

### **Sensitivity to Context**

To meet Yardley's (2008) principle of sensitivity to context, I have demonstrate meaningful engagement with my participants through well-facilitated interviews and communication with participants. My analysis sought depth and

cohesion of themes rather than breath and description of interviews. My knowledge of and continued immersion in the field of visual impairments and the QOL literature aided in shaping the study and forming careful, relevant conclusions.

### **Commitment and Rigor**

Commitment is evident in the focused interviewing and diligent investment of my time and energy to the transcription and analysis of participants' shared experiences. Likewise, my carefulness in selecting an appropriate sample, interviewing and following up with participants, and analyzing each transcript will speak to the rigor of my investigation (Smith et al., 2009).

### **Impact and Importance**

My aim is has been to provide a foundation for future studies with tremendous potential to improve the efficacy of human rights interventions for persons with disabilities. If this line of research is continued, the construct QOL will increase it its impact and importance in the fields of visual impairment, disability rights, and international development. Furthermore, the findings with respect to the experiences of the six participants have immediate and important implications for educators, community planners, researchers, and others concerned with supporting young adults who are blind.

### **Significance**

My intent has been to develop a theoretical basis for a new or revised quantitative instrument. My present hope is that these findings will provide a basis for a mixed-methods line of research, including future quantitative instrument development and dissemination, to assist the international efforts to develop evidence-



based interventions for improving the lives of persons with disabilities.

Additionally, I believe strongly in including the voices of people with disabilities in all research. Like many researchers in the special education field, I do not identify as a person with a disability, and I strongly promote research practices which are about “working with,” rather than “conducting studies on” participants. Inclusive research practices are not only socially just; they are also inherently more valid than research which is based upon what people without disabilities presume about people with disabilities. Conducting these interviews has further inspired me to share the words and stories of young adults who are blind. By providing authentic accounts of their experiences, I can inform additional research, education, professional preparation, social programs, and humanitarian interventions.

## **CHAPTER IV**

### **FINDINGS**

The concept of quality of life (QOL) should be an important consideration for any programs, services, and advocacy movements of and for people with disabilities. What use are efforts aimed at “disability rights” if outcomes do not include subjectively and objectively better life circumstances? As our understanding of QOL and its component constructs increases, instruments and indicators have been and will continue to be developed to measure and monitor the extent to which people are leading lives that are satisfying and meaningful. Thus, QOL is an important component in the identification and promotion of best-practices for human-rights, educational, and social interventions.

My investigation of existing QOL literature revealed considerable collaboration and research related to human rights and QOL for persons with disabilities around the globe (e.g. Karr, 2011; Schalock & Verdugo, 2002; World Health Organization Division of Mental Health and Prevention of Substance Abuse, 1995, 1997); however, only a few studies have considered a human-rights focused, internationally-oriented measure of QOL for populations which include persons with visual impairments (Rimmerman & Morgenstern, 2003; Verdugo et al., 2005). No studies have provided a validated, reliable instrument for measuring QOL in populations that include persons who are blind or visually impaired.

To address this gap in research, and to support the development of a valid and reliable QOL instrument for use with people with visual impairments, I designed a qualitative investigation employing interviews with six young adults who are blind.

### **Purpose**

In this study, I have taken an initial step towards ensuring that researchers, evaluators, and advocates can collect valid and reliable QOL measures in any inquiries that involve the lives of persons with visual impairments. Through extensive interviews, I explored how young adults who are blind experience QOL. My thematic analyses provide insights into what QOL means to my participants, and the themes I uncovered provide a starting point for the development of a theory of QOL for persons who are blind and visually impaired. Once this theory is refined, with future qualitative and quantitative studies, instruments can be validated and/or designed that are consistent with this theory and thus appropriate for populations that include persons with visual impairments.

### **Context of the Study**

In this section I describe the places and people involved in this study to the greatest extent possible while protecting identifying details about participants.

The purposes of my study, exploration and theory development, led me to the decision to conduct individual interviews with persons with visual impairments. Narrowing the population further to a specific age range (18-25) and level of visual acuity (below 20/1200) enabled me to target a group of people with similar experiences; however, this also increased my difficulties in locating participants. As a certified teacher of students with visual impairments, a doctoral student, and an advocate, I recognized the limitations imposed by the low-incidence of blindness in the general population; additionally, traditional participant recruitment methods (flyers, websites, emails, etc.) might not be effective for informing participants about

the study.

I elected to focus my recruitment efforts in a large state in the southwestern United States which is nationally respected for its state-wide outreach efforts and professional preparation in the field of visual impairment. This state includes many rural areas as well as several very large cities, with regions of great (and not-so-great) cultural diversity. All interviews were conducted between February and April, 2014.

Four of the participants lived in and were interviewed in the same large city, which is home to the state's school for the blind. This city has a public transportation system and a paratransit system, both of which are free for college and university students. I conducted these interviews either on the School for the Blind campus or at the participants' apartments.

One participant lived in and was interviewed in a suburban area near a different large city in the state. This suburban area did not offer a public transit system, and so the participant and I traveled in my car to various public spaces to conduct the interviews.

Another participant was attending a university in a smaller city in a more rural part of the state. This city does offer public transit (a bus system). I met this participant for interviews on the university campus.

### **The Participants**

All participants' names have been changed to pseudonyms. In some cases, descriptive details about participants have been omitted because revealing information would compromise the participant's anonymity. Table 3.1 includes demographic information which is supplemented by my narrative descriptions.

**Alex.** Alex was a 20-year old male university student who lived in his own apartment several miles away from the large, state university which he was attending at the time of the interview. He was an exceptional “cane traveler,” meaning a person with visual impairment who travels independently using a long cane, who reported numerous on-road and off-road traveling adventures. At the start of the first interview, Alex explained, “my views on what a quality life is probably aren’t going to coincide with most blind people. I have a rather unorthodox view, I suppose.”<sup>1</sup> (Note: all numeric superscripts in this dissertation reference the audit trail in Appendix C). He regularly expressed points of view and described experiences that were unique and often contrary to popular norms and/or best practices in the field of visual impairments.

Alex was treated for bilateral retinoblastoma at 21 months, which resulted in his blindness. His family relocated twice, both times in connection with finding the best medical treatment and services for Alex.<sup>2</sup> He received services from a teacher of students with visual impairments (TVI) and orientation and mobility specialist (O&M) from the age of 3 and was included with sighted peers in a typical pre-school and throughout his kindergarten through 12<sup>th</sup> grade (K-12) education.<sup>3</sup> In 9<sup>th</sup> grade, Alex took part in a two-month expedition to the Amazon rainforest with other teenagers, sighted and blind, as part of a research project.<sup>4</sup> At the time of the interview, Alex was planning to leave his university and his apartment to travel independently for an indefinite period of time, hoping to experience life among different cultures. With regard to this non-traditional adventure, he explained:

If I don’t have a place to come back to, I’m going to be forced to go look out,

and go seek those experiences out. Even if I don't seek them out, they're going to come to me. So I think that will be extremely useful. ... I very much find different beliefs and cultures fascinating. So, I've managed to identify and I talked to them, and I'm going to be staying in all of the different religious, kind of monastic equivalencies for a month or so for each one. To get an idea of that culture and that belief system, that sort of thing. You know, so I'm going to be staying in a traditional Christian monastery. I'm going to stay in an ashram. Hindu ashram. I'm going to stay in an Islamic temple. I'm going to stay in a Buddhist monastery. All these things. I think that will be extremely fascinating. And I'm also just looking forward to having the freedom to wake up one day and realize, "I really don't like this place. I'm going to go somewhere else." I think that will be great.<sup>5</sup>

**Brianne.** Brianne was a 19-year-old female student in a post-secondary transition program run through the state's school for the blind and the state's rehabilitation services department. She lived with minimal supports in her own apartment which shares a common area with three other students in the program. Brianne experienced difficulties with short- and long-term memory due to traumatic brain injury, and while she was a cane traveler, she struggled to learn complex routes. She explained, "I was working on the route from [rehabilitation center] to here, in like September, well August. Which that, I spent 3 months on, but finally got it."<sup>6</sup>

Brianne received the majority of her K-12 education in a neighboring state<sup>7</sup> but was pleased to have relocated, because "well, being here in [city] there's a lot more to do. It's a bigger city and not in a small town, so I can actually go places more, because there's more transportation. When you're in a small town, there's nothing. There's not taxis or city buses, trains. Yep they have all of that here which is awesome."<sup>8</sup> She was not able to recall her earliest introduction to TVI and O&M services.<sup>9</sup> Brianne reported that her vision loss is due to optic atrophy at the age of 5 months, but she was not able to provide additional details.<sup>10</sup> At the time of the interview, Brianne was wrestling with a decision of either transferring to a different rehabilitation program, as

recommended by her advisors, for additional training or trying to find employment and supports to move out on her own. She expressed,

I'm trying to get myself to be open to options because I want to graduate in May and just try to find the cheapest apartment I can and live on my own, but staff and stuff that are training me here, are talking to me about... [training center] in [city] where they teach us job skills, help us get a job, help us keep it, and it's like, I need that but I don't want to go through any more training. So, I'm trying to figure out what to do now.<sup>11</sup>

**Darik.** Darik was a 22-year-old male enrolled at a large state university. He lived in an apartment near campus which he shared with other university students. Darik self-identified as deafblind and was a dog guide user. Unlike the other participants, Darik was born outside of the United States and experienced challenges related not only to deafblindness but also to his status as an immigrant.

Darik was especially passionate about the support provided by his parents, saying,

...on the subject of things going well, even without finances to support me my parents, they are the ultimate symbol of things going well in my life because they made a choice to keep me even though I had a disability – and one of the ones that people for some reason find the most discomforting. And this is particularly true in societies in which physical ability is very important. In [country] culture, fathers routinely bond with their sons especially, over very physically intensive activities like volleyball, soccer, things that ordinarily require sight. So, to have a blind child is a very trying experience from which many [country] men would have run. And my father chose not to do that, and my mother chose not to do that, so their continued support was of course an example of things going well. And it's the reason why so much has gone well for me, because I've always had them in my corner.<sup>12</sup>

Darik's family relocated to a southern state in the United States when he was two in order for him to receive treatment for the bilateral retinoblastoma which caused his blindness.<sup>13</sup> He received services from a TVI and O&M specialist beginning at the age of 3 and was fully included with sighted peers throughout preschool and his K-12

education.<sup>14</sup> Following high-school, Darik encountered financial and logistical road-blocks which prevented him from immediately enrolling in university coursework. During part of that time out of school, he participated in a program at the state rehabilitation center.<sup>15</sup> At the time of the interviews, he was pursuing a degree in journalism and a career in radio journalism.<sup>16</sup> He explained,

When I was waiting to enter college, [National Public Radio (NPR)] was the only thing that really kept me sane. I listened to NPR day in and day out after leaving high school, ...and it just kept me sharp, kept me abreast of things.<sup>17</sup>

**Janessa.** Janessa was a 20-year-old female student in the same transition program as Brianne; however, her schedule also included courses at a local community college and an internship with a hotel chain. Janessa was a cane traveler who self-reported, “I have really good... perception of where I am, and once I go one way, I know how to reverse it.”<sup>18</sup>

Janessa became blind at the age of two as a result of bilateral retinoblastoma. She recalled receiving TVI and O&M services at her home around the age of 3 and throughout her K-12 education at her local, public school.<sup>19</sup> Following high school, Janessa attended a community college closer to her home city where she lived in a dorm; however, she decided to transfer to the program at the school for the blind.<sup>20</sup> She described that transition,

I was like, okay, I'll go to college, and that's what I wanted to do. So after high school I went to college, and, by the end of the first semester of college I was like, oh no. I want to go to [rehabilitation center]. Well, mainly because it was just I guess you could say I didn't really know how to cook on the stove much. I didn't have that – I had a little bit of practice but not as much. And I was like, I can't just go through college and cook in a microwave and order out all the time. I want to learn how to cook on a stove. And the college that I went to was in a small town, so it wasn't, there wasn't any buses or any kind of trains, or I don't even know if they had door-to-door service. If I even wanted to go somewhere. So I was like, no, I want to go to [rehabilitation center] so I can



learn these skills. And, when I came here I got more than what I wanted. I could say.<sup>21</sup>

At the time of the interview, Janessa was nearing the completion of her time in the transition program, hoping to remain in the city, with employment as well as housing and scholarship assistance, and finish her studies in hospitality.<sup>22</sup> She discussed obtaining a four-year degree and pursuing a career in hotel management.<sup>23</sup>

**Martin.** Martin was a 19-year-old male student attending a transition program run through the state's school for the blind and also attending classes at a nearby community college. He lived with minimal supports in his own apartment which shares a common area with three other students in the program. Martin was a cane traveler. He described his experience in the transition program,

Oh it's really cool... and, you know, they encourage independence... to the fullest extent, while still being supported in some areas, and I'm able to travel there independently to [community college], ask for what I need, on my own, and do my homework. And I, just, it's just really good experience, having that support as well as knowing that I am encouraged to be independent.<sup>24</sup>

Martin became blind at eight months of age following a bone marrow transplant to restore an imbalance in his immune system.<sup>25</sup> He attended public schools from the age of four through eighth grade when he transferred to the state school for the blind, and he was a resident on that campus, with weekend and summer trips home, from that time onward.<sup>26</sup> At the time of the interview, Martin was looking forward to exiting the transition program and enrolling at a state university closer to his parents' home.<sup>27</sup> He hoped to pursue a career in computer programming, which captured his interest when he began exploring computers in middle school.<sup>28</sup> He explained,

Computer programming kind of came about, me one time exploring how

websites were developed, and it was just a curiosity that I had. I started researching on Google... and I came across something known as HTML... I got acquainted with the HTML language, and then I started exploring even more advanced programming. ...So, after learning that HTML, I started researching more into another language called PHP..., SQL databases, and some more geeky stuff. That's basically where it started. Just me having my curiosity... I realized, I really, really enjoy coding. That's why, that's something I would really like to do as a career.<sup>29</sup>

**Tess.** Tess was a 22-year-old female enrolled in her final semester for her Bachelor's degree in French from a state university. She lived with her family in a suburb of a large, metropolitan area and was a very proud dog guide user, explaining "The best thing that ever happened to me by far is getting my guide dog. By far. She changed my life. I am who I am today because of her."<sup>30</sup>

Tess was born without a left eye and with an atypically small right eye, which was surgically altered to provide her with light perception and some color and shape perception.<sup>31</sup> Following Tess's birth, her mother received training and certification as a teacher of students with visual impairment and served as Tess's first TVI in their very rural area.<sup>32</sup> Tess received TVI and O&M services through the public school system beginning at the age of 4 with pre-kindergarten. Her family relocated to a major metropolitan area when she was 6 years old, and she continued her K-12 education in the public school system.<sup>33</sup> Tess described extreme episodes of bullying and harassment in high school as well as very distressing challenges with receiving necessary accommodations from her university;<sup>34</sup> however, she maintained a positive outlook, saying,

Hindsight is always 20/20, but, how do you know that if you would have gone, could have gone back and changed something? How would you know if that turned out well or not... If I could go back and change it. Well maybe I would have changed it back to a different high school or maybe I would have – how could I know if that would turn out well or not? I mean that's, that's not

something I think about a whole lot... Maybe you could change some stuff if you could go back. Maybe I could? Maybe I would? ... How can you know whether or not anything would've worked out, still? You never know.<sup>35</sup>

At the time of the interview, Tess was planning to enroll in a new university in order to pursue majors in additional foreign languages, having been unable to complete her studies in these areas at her initial university due to access issues.<sup>36</sup> With certifications and qualifications in multiple languages, she felt optimistic about obtaining a future career as a language translator, transcriber, and/or teacher.<sup>37</sup>

### **The Researcher**

As the researcher in this qualitative study, I have played an active role, both as the recorder and interpreter of the data and as the instrument through which the data was collected. The role of the interviewer is well described by Cassell, who wrote, "... the product of an interview situation is the outcome of an interviewer's own construction of their world and the given interview situation" (2005, p. 5). Therefore, to aid readers in understanding what experiences and ideas that I brought to the multiple research tasks (reviewing the literature, constructing the interview protocol, sampling participants, conducting interviews, analyzing data, etc.), I tell my story.

At the time of the study, I was a 32 year old female doctoral candidate with a Master's degree in special education, enrolled in a Ph.D. program in special education at a large, state university. During part of the project design, I lived on campus at the university, located in a medium-sized city surrounded by rural, farming communities. Towards the end of the study, I was living at my home in a more suburban, semi-rural area between two large cities. I identify as Caucasian, and I do not identify as a person with a disability. I have always had two loving, supportive parents, and I am married –

without children – to a supportive and successful man.

I was born in a southern state in the United States and have lived in southern states in the eastern and central United States my entire life. I received a Bachelor's degree in Psychology from a small, private university in a large city, and the majority of my post-Bachelor's degree employment has been with public school systems. I decided to pursue a certification as a teacher of students with visual impairments after having taught a student who qualified for TVI services and learned about the field. During their retirements, my maternal grandmother had been a volunteer brailist and my maternal grandfather had repaired brailers and audio book players, and I had always enjoyed the unique challenges that come with working with students and adults who approach the world in a unique way, due to sensory or other differences.

With respect to QOL for persons with visual impairments, I am persuaded by the IASSID's SIRG QOL model and the work of Schalock and Keith and others to develop a human-rights-oriented QOL instrument for use with diverse populations. I am also intrigued and impressed by the extensive work done by the WHO to adapt and study their QOL instrument in a variety of cultural contexts. I believe that a human-rights understanding of QOL is likely to consist of the same basic elements, with varying prioritizations, among all populations. However, as I have conveyed through the purpose of this study, I believe that it is imperative to consider the actual, lived experiences of persons with visual impairments before presuming to know whether or not existing models and instruments are an appropriate fit.

### **Themes**

Six over-arching, interconnected patterns emerged from my cross-case analysis

of the eighteen interview transcripts. While I uncovered and coded numerous concepts described by participants, in the consolidating and categorizing of these codes, I purposefully strove to emphasize those factors which contribute either positively or negatively towards QOL. The remainder of this chapter describes those over-arching themes (from here on referred to as *themes*) and important subthemes within each theme. Figure 4.1 provides a conceptual overview of the themes and their interconnections, and Figure 4.2 lists the themes and subthemes described in this chapter.



*Figure 4.1* Major quality of life themes. The six themes, *external support systems*, *interdependence*, *internal support systems*, *independence*, *experiences*, and *knowledge and skills*, are inter-related. For example, experiences which contribute to quality of life both necessitate independence and help build independence.

In the above configuration, six hexagons, each labeled with a theme, have been arranged in a circular pattern so that each hexagon is adjacent to two other hexagons. This arrangement represents one way to understand the interrelation of the major themes. *Knowledge and skills* is positioned between *external support system* and *experiences*, because *external support system* and *experiences* contribute to and are influenced by *knowledge and skills*. *Experience* is positioned between *knowledge and skills* and *independence*. *Independence* is positioned between *experiences* and *knowledge and skills*. *Internal support system* is positioned between *independence* and *interdependence*. *Interdependence* is positioned between *external support system* and *internal support system*. *External support system* is positioned between *knowledge and skills* and *inter-dependence*. The arrows in the center of the circular arrangement of hexagons indicate that there exist many additional relationships among these major themes; this particular relationship was chosen to illustrate some of the stronger relationships based on my own understanding of the data and themes; additional research is needed to better understand these relationships. The term “Quality of Life” in the center of the figure conveys that all themes are connected with this core concept.

My description of this figure has been especially detailed in an effort to explain the rationale for this particular arrangement of themes and to provide greater access for readers with visual impairments.

External support system	Experiences	Interdependence	Independence	Knowledge and skills	Internal support system
<ul style="list-style-type: none"> <li>• Education and learning</li> <li>• Blind community</li> <li>• Technology</li> <li>• Equal access</li> <li>• "Blind-friendliness" of surroundings</li> <li>• Money</li> <li>• Family</li> <li>• Efficiency</li> <li>• State and social programs</li> <li>• Safety and security</li> </ul>	<ul style="list-style-type: none"> <li>• Doing something meaningful</li> <li>• Going places</li> <li>• Outlet</li> <li>• Making mistakes</li> <li>• Being in motion*</li> </ul>	<ul style="list-style-type: none"> <li>• Accepting help</li> <li>• Being social</li> <li>• Insensitivity</li> <li>• Integrating with sighted people</li> <li>• Being accepted and included</li> </ul>	<ul style="list-style-type: none"> <li>• Self-determination</li> <li>• Self-reliance</li> <li>• Self-advocacy</li> </ul>	<ul style="list-style-type: none"> <li>• Orientation and mobility</li> <li>• Braille</li> <li>• Daily living skills</li> <li>• Math</li> <li>• Writing*</li> <li>• Career and college preparation</li> </ul>	<ul style="list-style-type: none"> <li>• Confidence</li> <li>• Working hard</li> <li>• Contentment*</li> <li>• Adaptability*</li> <li>• Proactivity*</li> </ul>

Figure 4.2 Themes have been presented in order of greatest to least prevalence in the transcripts (left-to-right). Sub-themes have been presented in order of greatest to least prevalence in the transcripts (top-to-bottom). Prioritization is not implied.

\* indicates a sub-theme represented in the interviews of only five of the six participants

## Overview of Themes

As shown in Figure 4.1, factors contributing to participants' QOL can be represented under the major themes *external support systems*, *interdependence*, *internal support systems*, *independence*, *experiences*, and *knowledge and skills*. These six themes are found multiple times in each interview and for each participant. Table 4.1 shows the frequency of text segments connected with each theme for each participant.

Table 4.1

*Frequency of Text Segments Connected with Major Themes for Each Participant*

Theme	Alex	Brianne	Darik	Martin	Janessa	Tess	<b>Total</b>
External support system	138	103	132	130	95	300	<b>898</b>
Experiences	80	35	77	52	59	125	<b>428</b>
Interdependence	54	36	70	41	45	134	<b>380</b>
Independence	49	22	50	32	31	54	<b>238</b>
Knowledge and skills	33	31	35	31	16	41	<b>187</b>
Internal support system	23	6	41	19	19	48	<b>156</b>
Total text segments	377	233	405	305	265	702	<b>2287</b>

Figure 4.1 highlights the interconnectedness of the themes and the way in which two or more themes support each other. For example, participants' knowledge and skills and their level of independence allow them to access the external support system. Of course, my six-theme interpretation is only one way to represent the interconnectedness of themes; additional research is needed to better understand the complex relationships and the interactions of subthemes within each theme. The following sections discuss each theme in detail, reviewing themes and the subthemes in order of prevalence in the transcripts.

### **External Support System**

One direct consequence of having a sensory impairment in the modern, sensory-rich world was that the participants in my study had to rely on people and organizations, not only for specialized and adaptive assistance, but also to access and receive services that people with full use of their vision take for granted. Fully



accessing this external support system also involved other major QOL themes, including *interdependence* – for interacting with and relying on others, *independence* – for self-advocating and accessing services, *knowledge and skills* – for identifying and making efficient use of services, and *experiences* – through which to learn from mistakes and interact with others.

The participants did not directly discuss the idea of an external support system but rather described their interactions with components of such a system. To categorize participants' statements as related to the external support system theme, I looked for connections with people, organizations, or resources upon which the participants had to depend at the time of the interview or in the past in order to reach a goal or maintain their existing lifestyle. The sub-themes for this major theme include particular categories of resources (education and learning, technology, money, family, the blind community, state and social programs) as well as characteristics of those resources which were important to participants ("blind-friendliness" of surroundings, equal access, safety and security, and efficiency). Table 4.2 details the frequency of text-segments for each of these sub-themes in each participant's transcripts. While participants cannot and should not be compared against one another due to variations in the length of each transcript, the within-participant variations in subthemes is telling of what preferences or experiences were significant to each participant in his/her external support system.

Table 4.2

*Frequency of Text Segments Connected with External Support System Subthemes for Each Participant*

Subtheme	Alex	Brianne	Darik	Martin	Janessa	Tess	Total
Education and learning	<u>31</u>	10	<u>27</u>	17	<u>18</u>	28	<b>131</b>
Blind community	13	4	19	18	7	<u>48</u>	<b>109</b>
Technology	22	9	13	<u>20</u>	9	33	<b>106</b>
Equal access	11	13	12	<u>20</u>	4	45	<b>105</b>
“Blind-friendliness” of surroundings	8	14	11	11	14	32	<b>90</b>
Money	7	<u>18</u>	11	12	13	23	<b>84</b>
Family	9	9	13	11	1	18	<b>61</b>
Efficiency	11	3	9	3	11	10	<b>47</b>
State and social programs	2	7	3	4	5	11	<b>32</b>
Safety and security	9	2	1	3	2	11	<b>28</b>
Other	15	14	13	11	11	41	<b>105</b>
Total text segments	138	103	132	130	95	300	<b>898</b>

*Note:* Underlining indicates the subtheme(s) most frequently reported for each participant.

**Education and learning.** More coded segments in the external support system theme were connected to the subtheme of education and learning than to any other subtheme. Education and learning occurred both through formal education systems (such as K-12 and university programs) and informal learning environments (job sites, homes, etc.), involving trained and untrained educators. For many participants, the process of education was a goal in itself, and an important part of a quality life. Darik

explained his love of learning (and National Public Radio [NPR]) this way:

What NPR showed me is that there are people who are interested in many things, but they channeled their interests. They can channel it into a productive life. They made their curiosity work for them. And I was like, “Yes! This is exactly what I need to do.” Instead of becoming a perpetual student, which is not a good way to make money, I can become a journalist. Which is not a good way to make money either, but you make, you can make a living. And still learn, which was my *ultimate thing* [emphasis added]. I wanted to still be learning and teaching.<sup>38</sup>

Of all the participants, Brianne expressed the most frustration with her K-12 education. She conveyed how an absence of education could negatively impact QOL, lamenting during a discussion of learning how to budget money, “I mean some kids just have to be around people that don’t teach them things, like that. Or don’t teach them at all.”<sup>39</sup> For Martin, higher education represented an important element of QOL, stating that to assess QOL, he would look at “living arrangements, employment, or whether that person is pursuing higher education.”<sup>40</sup>

Many participants also emphasized the importance of learning through self-teaching and authentic experiences. Tess explained her challenges with independently exploring and traveling by saying,

I think part of it is the area I live in isn’t always pedestrian friendly here. So I think I might be better at that when I am living [another city]... They are a lot more pedestrian friendly, but, again, I think the only way I’ll really learn that is by traveling the area. You know? Just doing it. ...I would say generally... my family and my friends have done a pretty good job helping me learn, you know. I just have to buckle down and do it [laugh]. I think that’s what life is most about, you know? You learn and you read. You read the stuff, and you read how to’s and you learn from friends and family. But at some point you’ve just got to button-down and do it. Sighted people too, you know? You’ve just got to do it. Be brave!<sup>41</sup>

In contrast with the field of special education for students with visual impairments’ current emphasis on formal instruction of social skills, several

participants strongly supported the notion that social skills and skills for independent living should be taught at home and/or learned on one's own. Alex said:

I mean the social skills come on their own, right? Those come from interactions with other people... if you don't learn that you can't be taught them. That's kind of how I see it. If, you know, you learn them by practice. It's very difficult to teach someone how to not be awkward, not be tense, not react incorrectly. You just kind of have to pick that up. So social skills not so much. Daily living skills... I eventually moved out and found myself in a kitchen looking at the burners, at the stove, going "hmm," I've only ever used a microwave. Here we go. So my first couple cooking adventures were that, adventures. Quite terrible. But I've actually found a passion for cooking, I love it.<sup>42</sup>

Likewise, learning from parents played an important role. When asked if he spent any time with a TVI learning independent living skills, Darik responded,

No. Because that's what your parents teach you... the presumption that the only way for blind people to learn independent living skills is if you set aside two hours a day to teach them to fold clothes and cook – No! That's what parents do. Unless the parents are buying into that presumption as well. "Oh, wait for your TVI to teach you how to fold clothes." No.<sup>43</sup>

However, Brianne expressed a different opinion,

Because sometimes [people who are blind] don't have parents that will teach them... and they may not have parents that emotionally are there, or physically. So they have to, it would be better for them to be able to have someone that cared, or that would help them learn.<sup>44</sup>

In all cases, education and learning were emphasized as essential to success and a quality life.

Most participants also discussed times when they had learned valuable academic and life skills and information by working with other blind people. Martin explained that he learned Japanese braille from an intern at his school who was also blind,<sup>45</sup> and Janessa shared how a teacher and mentor impressed her with the notion of college sororities:

There is this one blind teacher, she's, I think she's totally blind, and she's at [rehabilitation center]. I just met her this year. She'd done something that I really wanted to do, in college, she was in a sorority. And she told me about this. And, she's like oh yeah, that was really fun... And to know that she has a job now, she can, like if she travels and she doesn't know that city, she can call up any sorority sisters and ask them like, "Hey are there any people that's in this city that might could help me get here?" ... and that's how she gets a chance to know what's around.<sup>46</sup>

Finally, in connecting their education and learning to QOL, all participants expressed the importance of having good teachers.<sup>47</sup> Based on her own K-12 experiences, Brianne believed that her education would have better prepared her had she attended a residential school for the blind because

you would learn a lot more, and there would be... a lot more accommodations. People are a lot more educated. I mean... in public or regular schools, they're not as educated as to what to teach, how to teach, but the people that work for a school for the blind, they have to be educated because they have to teach it.<sup>48</sup>

Janessa had a different experience in public schools but also saw great value in quality teaching, saying, "I was very blessed to have some great VI teachers and great O&M teachers to work with me. To get me through my blindness... and to get me to be the adult that I am today."<sup>49</sup>

**Blind community.** Another subtheme of the external support system described to varying extents by all participants was the broader "blind community," consisting of people and organizations with the common experience of blindness and/or visual impairment. Martin was perhaps the most immersed in this network as he both lived on the campus of the school for the blind and volunteered with a national membership organization for people who are blind.<sup>50</sup> However, Tess felt an equally strong connection to the blind community through formal and informal networks of dog guide users.<sup>51</sup> She explained, "...they don't totally understand what it's like to be me,

the ones who are sighted; the ones who are blind understand.”<sup>52</sup>

The low-incidence of blindness and visual impairments often results in students growing up knowing very few other people who are blind or visually impaired. Tess described how her experience with the blind community was different when she was younger, saying,

...it’s probably worth mentioning, before I got my dog, I didn’t really hang out with blind people. I didn’t want to hang out with blind people. Because, and, like, I know this will sound awful, and I love, I love blind people. Especially blind people who may be not, like totally academic like I am. You know what I’m talking about? Like, totally functioning, whatever. I love them. Okay, but in my 14, 15, 16-year-old mind, I wasn’t like them. I didn’t have much that I could identify with them. So I didn’t, I wasn’t one to want to go be part of the blindness community.<sup>53</sup>

Janessa shared that she was also not connected with the blind community when she was younger, but,

as I got older I started going to events and getting a chance to meet other different blind people in my community. ...It’s a small world so, like guarantee somebody might know someone even though they might be from a different city, or maybe even a different state, they still know, might know that person, because of an event that happened.<sup>54</sup>

Alex, who described himself as having views outside of the norm for “most blind people,”<sup>55</sup> and who was not especially drawn to participate in the politics of a national membership organization,<sup>56</sup> still expressed positive experiences with networks of goal ball players and with fellow online gamers who are blind or visually impaired.<sup>57</sup> Likewise, Darik found a community of friends among other young adults with deafblindness, together with which he has helped to form a national advocacy organization.<sup>58</sup> He described how this group has impacted his QOL, saying:

And, through [group] especially, I met people like myself, intelligent, driven, knew a lot about a lot of things. They weren’t exactly like me, which was perfect, because you don’t want exact replicas of yourself. You want

differences. People with different views. But they are all smart, independent, and they have figured out ways of dealing with life while being deafblind. Which is what I needed to know. I needed to know what the alternatives were, what the options were. What was available? I needed to know how to use a braille display to access the Internet. I needed to know about tactile sign language, about pro-tactile ways of communication. And this community gave that to me. It also gave me the desire, the impetus to own my deafblindness. I saw them doing it, and I was like, “Okay. I can do that, too.”<sup>59</sup>

For Brianne, who expressed having few friends among her sighted peers, the local community of students in the rehabilitation and transition programs formed a peer group and support system for her.<sup>60</sup> At the time of the interviews, both Brianne and Alex shared that they were dating other people with blindness or visual impairment,<sup>61</sup> and none of the participants described dating sighted peers.

**Technology.** Another very common subtheme under the theme of external support system was the use of, access to, and pursuit of technology. Technology’s rapid advancements mean that a host of high-and-low tech devices are potentially available to people of all ages to improve their access to and inclusion in mainstream activities. Not surprisingly, the participants’ conversations about their experiences related to QOL frequently turned to their hopes, dreams, trials, successes, and frustrations with technology.

Like education, participants both aspired to accessing technology as part of a quality life and made use of technology to achieve other goals. Technology is also connected to subthemes within the external support system theme (especially education, equal access, blind-friendly surroundings) as well as other major themes (e.g., independence).

Tess described how her access to independent learning opportunities in online courses and language labs was thwarted by a lack of technological accessibility at her

university:

... I wasn't allowed to take a Spanish course online because it was inaccessible. And everyone else in the university was... [W]hen I finally did take Spanish... I made a C instead of an A because the lab was inaccessible. They made a, pardon my French, but a half "a-s-s'd" effort... I made a C instead of an A, because ultimately it was decided by the professor and the university that I just won't do the lab... if I have been allowed to do lab, it was a simple completion grade. I'd have made an A. I'd have made like a 93.<sup>62</sup>

Martin was pursuing a career in technology and frequently discussed both his experiences in finding ways around accessibility issues and his desire to stay plugged into the latest technology for his career. He said,

You know, I – I've been lucky enough to gain a lot of knowledge about how to navigate the websites. Even if they're not accessible... I can find workarounds and do all these neat tricks, but, somebody who's not as knowledgeable might not have the patience or might not want to try to navigate the website. You know? They want it to be simple and accessible. But I think that, for me at least, I'd say 60% of websites that I've navigated are pretty accessible.<sup>63</sup>

Martin also explained,

As a computer science major, I do think that having access to the latest technology is really important. So, I think that I'm going to have to rely on gaining employment and earning the money necessary to pay for technology and, you know, saving up for that kind of stuff, or maybe getting contact with blind related organizations that would be able to purchase that.<sup>64</sup>

People with visual impairments have a variety of interests and ways to use technology, as evidenced by the participants' diverse descriptions of the tools they use for various purposes. Janessa described how she would need to have JAWS, an expensive text-to-speech software, installed on the computer at her internship site in order for her to complete a rotation as the hotel's front-desk clerk,<sup>65</sup> and Brianne expressed both frustration with and an appreciation for Microsoft Excel as a budgeting tool. Brianne explained, "My post-secondary staff here have been teaching [budgeting] with Excel, which I hate Excel, I'm just saying, but it's helpful."<sup>66</sup>



Most every participant expressed ways in which mainstream technology was equalizing access for persons with visual impairment. Darik did not have access and skills for searching the internet and applying for scholarship and jobs until he was in college, and he regretted missing out on the benefits he might have received had he gained access to the internet at an earlier age. He described helping his younger sisters apply for part-time jobs, saying,

... and back to the question of technology access again, [they] went online and pulled up an application... and they just went through the application process. And I sat there and I helped them fill it out. And I was just thinking to myself, well, I did not have this when I was younger. I didn't have this access.<sup>67</sup>

Similarly, Alex praised Apple's iPhone (with off-the-shelf, non-visual accessibility) and the freedom that it would give him during his planned adventures,

I actually have a laptop, but I don't use it anymore... For a while now all I've used is an iPhone and the Bluetooth keyboard. Which for all intents and purposes functions as a laptop... I'm going to get a new iPhone with 64 gigs of data so I can carry all my documents on there. I'm scanning everything in, and with that keyboard I can do all the writing I need, I can do web control, HTML coding, anything like that if I need to. And I'm going to be carrying these packs that carry extra battery life... so if I need to, my phone can go self-sufficient without a charge without an outlet for a couple weeks... The iPhone is such an equalizer on the technology playing field.<sup>68</sup>

Participants also described their experiences of understanding technology's limits, of a tendency to over-rely on technology, and of being able to cope when unplugged or offline. Brainne said,

Well, what if the computer crashes? Or – because I mean technology is not perfect all the time – there's some, it messes up every now and then. So personally, I think that learning braille, just in case, would help. Just in case technology does do something like that... Or just in case that particular computer does not have a screen reader on it, and there's no one there to read it to you. How are you supposed to access the information?<sup>69</sup>

Martin also warned about the potential for technology to replace typical, offline social

interactions.

I think that Facebook is just... being a substitute for the social aspect of life, because a lot of people have in mind that, "I'll just talk to somebody on Facebook, and if I say something or if I say a certain thing, there aren't going to be consequences." ...You know, it's just virtual. But sometimes... they're excessively getting on Facebook just to find out what every person is doing. I think that it's just people, the blind students have to be encouraged to go out and meet friends, and if they're being offered to go out to the movies with someone, I think that they should just go for it.<sup>70</sup>

**Equal access.** An important part of an external support system for people who are blind or visually impaired is the extent to which they have equal access to the supports surrounding them. Every participant described multiple issues with accessing the same supports available to their peers, especially Tess, whose consistently encountered access issues at her university which posed roadblocks for her educational and career goals.<sup>71</sup> She said, "It's like, what do you do? I'm in the middle of a class, I need the credit. I don't want to fail. What do I do? You know, they won't accommodate. What do I have to do?"<sup>72</sup>

Despite his admiration for his iPhone, Alex also described many access problems, recognizing that solving the problems is a responsibility of both sighted and blind people:

A lot of technology is still inaccessible... a lot of apps are inaccessible. And a lot of new forms of entertainment, a lot of new forms of research, and anything like that is still very, very inaccessible... [T]here are a lot of barriers in professional fields, career fields. I still feel that there is prejudice regarding whether or not a blind person can do certain activities, whether that be in the medical field or other fields. There are exceptional blind people who forced the field to accept them, but they are the exceptions. I think it is necessary, but I also think that is something that has to be reached as a compromise by both the blind and the sighted community. Those barriers are not going to go away until blind people are independent, saying that they can do these jobs and prove it. And once that is shown and demonstrated, I feel that corporations and companies will be likely to agree. But they're not going to just take our opinion on face. And nor should they. That's just a poor business model.<sup>73</sup>

Some of the access issues experienced by participants, including Tess's difficulties at her university, were violations of laws like the Americans with Disabilities Act (ADA). Brianne described how she was permitted to run on her high school track team for one year, but the following year she was told that her use of a sighted guide, running *behind* her to help her stay in her lane, was not fair to the other runners, and she was removed from the team. She said, "I was pretty upset. I mean I had just worked my butt off to get to this first track meet, and I was sore, and it was horrible. I was like, 'Seriously?'"<sup>74</sup>

Both Darik and Tess experienced ADA-related access issues connected with their experiences as dog guide users.<sup>75</sup> Darik shared,

I was going to catch a bus, but we accidentally turned into a restaurant while we were walking on the way to the bus. Which is a... restaurant... that I frequent very often, actually... [M]an, did they go, like "Ah! Get the dog out of here! Can't have the dog! They might come and inspect us..." and I tried to... show them that the law was on my side, but... I wasn't trying to eat there or anything, so I was like, "Fine! I'll educate you guys later."<sup>76</sup>

To resolve access issues, many participants shared a preference for supports and tools that are inherently accessible to everyone, rather than specially modified for people who are blind. Specially modified tools can be expensive and hard to find, whereas universally designed tools are useful to a wide audience of people with and without disabilities and are therefore more common and less expensive. Alex shared,

I think I advocate a lot to not modify. I feel like there's a big drive to modify everything. You can go on the Internet and see cooking utensils that are modified in so many ways. You can get measuring spoons that are labeled. Why? They're all different sizes? You can tell which one is which.<sup>77</sup>

Interestingly, Tess had a different experience with kitchen measuring tools. She preferred inherently accessible, commercially available tools and was even willing to

take steps to adapt commercially available tools after she purchased them, but she shared, “[Y]ou can’t necessarily make your average set of measuring cups accessible... If you are dealing with thin liquids and you need the liquid to be announced, you need an accessible measuring cup.”<sup>78</sup> Thus, for some tasks, Tess felt that she would continue to need to purchase products designed for people with visual impairments.

**Blind-friendliness of surroundings.** The idea of “blind-friendly” spaces and places came up during most interviews and was particularly poignant to Janessa. She found the city where she was living and working to have many benefits for people who are blind. She explained,

...Most of the people here, they know blind people, and they probably get asked questions, and they already know how to help you. Even, even the people that might be in high school or middle school, those are the people that don’t know much about blind people, and it’s good to see that they know, and know how to help you....living in a city where most of it is, or like 25% of it is blind people. And they already know that over there are schools for the blind, for the Deaf. And they already are surrounded by people who have disabilities.<sup>79</sup>

Her significant over-estimate of the blind population of her city is evidence of the impact of the “blind friendly” support system in her community.

Perhaps the strongest determiner of blind-friendliness for participants was the availability of public transportation and pedestrian routes through communities. They recognized the limitations on QOL that result from living in rural areas, which typically do not offer transportation options. Martin advised,

Well I wouldn’t know because I’ve never lived in a rural area, but, I mean, my suggestion would be to, you know, move into a city with a family member or something, because the city will definitely offer, more support and more accessibility, at least in my opinion. In terms of public transportation, just in general.<sup>80</sup>

Darik explained how having limited transportation options prior to moving away to

college impeded his independence, saying,

If I wanted to go somewhere, I asked my parents or asked a friend if they would be able to do it. Now, when I went to [city] and got access to the Internet, I fell into a very, very advanced public transit system, I realized the incredible benefits of that. And frankly, for a good while, I was saying to myself, “man! I cannot move back [home] after having experienced [city],” because to be able to hop on a bus with a suitcase, go into [grocery store], get all the groceries I want, hop back, go home. Within the space of two hours, it’s just independence. True, absolute independence. You know, even more so than waiting for paratransit... The bus system – totally much more independent than that, and I could not imagine going back home and depending on people with cars to take me places. This actually became a little bit of a point of contention between me and my father, because he was like “yeah, you are going to live in [home state]. [Home state] is a nice place, you know... you know, me and your mom will take you where you need to go, no problem.” I was like, “Yeah! It’s a problem for me,” because, I just don’t want to depend on people that way. It’s just not true independence if you have to, if your life depends on someone else’s schedule.<sup>81</sup>

Tess discussed in detail her thoughts on blind-friendliness and transportation,

summarized here:

Your small town or blind-friendly neighborhood, *emphasize neighborhood*, has to be pedestrian friendly – must! – and/or public transit... if it’s a small enough area that it doesn’t have public transit, but it’s totally walkable, it’s totally pedestrian friendly... as blind friendly as I’d consider a large city with mass public transit. But... even here... you’ll drive around, you’ll find the areas where there are not sidewalks. There are just chunks missing. It’s not pedestrian friendly where there is no curb cut... So, I would not consider my area pedestrian friendly. I can’t walk from here to my house without experiencing multiple sidewalk-less areas, where there’s all kinds of holes in the ground. It’s just not a good idea. So I would say the number one deal for a small neighborhood or town would be pedestrian friendly. For a large city, public transit is number one. And pedestrian friendly is number two. I mean, you needed to be friendly once you get off the bus. I would say in a small town or small neighborhood, public transit maybe isn’t necessary, but if you live in a big metro area like me, then it is... Because if you don’t have a way to get around independently, then I don’t care what else a city has going for it. It’s not blind friendly. You know, if you can’t get around by yourself, you’re screwed.<sup>82</sup>

**Money.** Financial issues were another major component of participant’s

external support systems and certainly impacted their QOL, even if they did not see

money as an important goal in itself. To ensure that he would be able to pursue his goal of traveling independently for an indefinite period of time, Alex said,

I am doing quite a few things. I'm setting up a travel blog website which I'm going to be running through affiliate sites, affiliate links, Google Ads, things like that... So, the traffic that I get will be providing royalty fees. Beyond that I'm also going to be working with a couple magazines... and things like that who have given me agreements for contracts. To publish writings of mine, travel writings, simply because there is – to my knowledge – no other perspective of a person who is totally blind traveling indefinitely... So that's going to bring me some income as well, I'm also running a Kickstarter program... That's going to bring in enough to do startup costs. I'm also, in a really fun way getting a bartending license, because there's a bar in every city that you go to. So, that could be a fallback if I need to. I'm also getting a court reporting license, because again, there's a court in every city. But beyond that I'm actually not anticipating an enormous amount of expenditure. ...Food will be the main thing, food and luxuries, when I want them. But I'm not so worried about money... it's never been a huge motivating factor for me. Money is something that I also consider somewhat irrelevant. At this point it's just a bunch of data points.<sup>83</sup>

However irrelevant to his ultimate satisfaction in life, having financial resources clearly factored into his plans and his ability to pursue his goals.

For Brianne and Janessa, being able to support themselves financially was becoming increasingly important as they prepared to exit the built-in external support system provided by the rehabilitation center and their transition program. Brianne was concerned with the cost of housing if she remained in her current city as well as her own abilities to budget money and shop independently,<sup>84</sup> and Janessa described some of the financial limitations of public assistance,

... I can't live on [government assistance] for the rest of my life, because it's so much that they can give you, and sometimes it's, it's not enough, and say if you get on housing you might have to be in housing at the most crappiest place, and that's not where I want to live.<sup>85</sup>

Money also impacts access to other aspects of the external support system, including transportation options. Darik remarked that using a cab – the only public

transportation option for some of the trips he wanted to make when living at home – was prohibitively expensive for a college student.<sup>86</sup>

**Family.** All six participants discussed the important role that their families – especially their parents – played in their external support systems. For most, this was an especially positive role, interspersed with conflicts of opinion as the young adults asserted their independence. Martin described his family’s support through his transfer from public school to the state school for the blind, saying,

Well, they’ve been really supportive for sure. You know they, starting from the first day that I was here, they asked me, “You don’t have to be there the whole entire year if you don’t want to. We can send you back to public school.” And they supported my decision to stay here for the past couple years, even though they wanted me to come back home.<sup>87</sup>

Darik said that he appreciated his parents’ particular sensitivity to the amount of support that he actually needed. He explained

I can congratulate them on not coddling me. Support can get to an extent where, you know – helicopter parents. Pick them up, carry them here, carry them there, drop them off, and pick them up again. That kind of support can be very stifling. I would never have been able to come out here to [university town] from [home state] on my own, if my parents had not recognized the value of independence for me to be successful.<sup>88</sup>

For Brianne, micromanagement on the part of her mom was seen as a major hindrance to independence and QOL.<sup>89</sup> Janessa expressed how parental over-protectiveness contributed to tough times for her as a teenager:

I felt like I was a good student in school, throughout elementary to high school. And when I came home, all I did was, I did homework first and then I turned on the TV. But... it was like I didn’t really go anywhere much... If I wanted to go somewhere, my parents always had this big question, “Well who’s going to be there to watch you?” and “I don’t know their parents, I’ll have to meet their mom, their dad,” or whoever was going to be there with us, and to make sure that I was going to be okay... And so my mom was mainly the one that always brought it up, “Well who’s going to be there and watch you?” And I would go to my dad. I was like, “Y’all don’t understand.” I was a good student... It’s not

like I would run off with someone that I don't know. And, he was like, "Okay, I'll talk to your mom." And sometimes it didn't go my way... he wanted what was best for me but also he agreed with my mom and said well, "Yes she's right." And I don't know. It really, it was a bad time. But there was also the good times when my dad would disagree... it was just in between.<sup>90</sup>

Tess considered herself especially lucky that her mother pursued special certification to teach students with visual impairment,<sup>91</sup> but she also expressed a strong bond with her father, who was her favorite movie describer and who co-commentated with her when they produced online radio of her high school football games for two years.<sup>92</sup>

**Efficiency.** Another common subtheme in participants' experiences with their external support systems was the concept of efficiency, which connected to almost all other aspects of this theme. Accessing a world which is designed for people who are sighted requires significantly more time, whether for shopping, cooking, traveling, studying, or taking tests. Therefore, people who are blind strongly prefer supports which are as efficient as possible, and they are often frustrated when asked to complete inefficient or superfluous tasks.

Alex, expressed frustration with most approaches to formal education which he felt required him to do extra work to visually represent his knowledge, even though his understanding of the subject matter had nothing to do with a visual representation. He described an instance in which, "the diagram that I'm being asked to visually represent is a diagram for a piece of homework that makes sure that I can put into practice something that I already know. So I am, for repetitions sake only, doing something that is excessively difficult for a blind person."<sup>93</sup>

Both Alex and Tess expressed a preference for accessing information via text-to-speech/audio, rather than braille, for the sake of efficiency.<sup>94</sup> Tess explained, "I



personally – and like I said, it’s going to be different depending on who you ask or talk to – but for me personally, I would rather have information on my iPhone or read to me by a screen reader, than braille because I can process information faster. And if you have a lot of information – like in a textbook or a document – to process, it’s faster to do it via audio.”<sup>95</sup>

The subthemes of technology and efficiency are certainly interrelated, with computer-based tools enabling people with visual impairments to more efficiently exchange text-based information. Janessa explained that the new tools she is using as a college student make her much more efficient, “I [can] email my teachers and turn in homework. Before college, I had to have my TVI teachers to transcribe my math papers and any papers that weren’t in braille that needed to be transcribed.”<sup>96</sup>

**State and social programs.** All participants discussed receiving services from various state and social programs, including federal, state and local agencies. The most common type of support discussed was Supplemental Security Income (SSI), which is provided to persons with disabilities from the federal government. Some participants expressed strong opinions about accepting government assistance, dispositions which connected this sub-theme with the themes of interdependence and independence and sub-themes of self-reliance and of accepting help.

Brianne was not working and had limited her contact with her parents following heated arguments over her independence and right to manage her own SSI income. She relied on public assistance for all of her expenses, although she recognized that she would need at least a part-time job in order to afford to live independently outside of the transition program.<sup>97</sup> Yet, the current SSI system

becomes problematic when recipients seek employment because the benefits decrease in proportion to the participants' earned income, creating a catch twenty-two scenario that could potentially dis-incentivize people to work. Tess explained one of her frustrations with SSI this way:

...it can impact your outlook on life and certainly your quality of life if you are on a lot tighter budget and you are low income or whatever. And certainly, like we talked about yesterday, my struggle to find work and deal with that, and juggle that with SSI obligations and stuff. But SSI mandates that I can't have over \$2000 at a time. Yet, somehow I would be technically allowed to own a car and a house. Explain that one to me? How am I supposed to own a car and a house with, if I can't have \$2000, period, on me at all?<sup>98</sup>

The state's department of rehabilitative services was another component of the state and social services support system that impacted participants' experiences. Martin – who grew to have a passion for computers and was preparing for a career as a computer programmer – first received access to his family's computer through text-to-speech software installed by his caseworker in the state rehabilitation department.<sup>99</sup> This same department ran the rehabilitation center where Janessa and Brianne were taking classes and where Darik had attended during a previous year. Janessa described some of the benefits of this center:

Well, being here, or going to [rehabilitation center], I learned a lot of skills. As far as like O&M, I learned how to travel by myself, I learned that I don't really need anyone to go places with me. And [in]... daily living skills I learned how to cook.... And then, technology, I, well I learned more on Excel and Word, things that I never knew before. I plan to apply them in the future. Also, career guidance, which is really helping me with the looking for maybe jobs, or school, or like apartments, anything that I need to look up now.<sup>100</sup>

An important aspect of this subtheme of state and social services was the extent to which they could be relied upon to deliver needed supports at various pivotal times during participants' lives. Not all state and social programs were seen as always

necessary or beneficial. Darik described his family's "winging it with the TVI department," and not connecting with his state rehabilitation agency until his senior year in high school.<sup>101</sup> Alex expressed not having a real need for the state rehabilitation agency's services until he started planning for his independent travel, saying "for all intents and purposes, I haven't gotten services from them in a decade, and now I'm finally asking for them."<sup>102</sup> Brianne was not happy with an overly-restrictive summer camp program offered by a non-profit, social-service organization – "... they would keep your suitcase and every time you need something you would have to go ask them for it... I was way too independent for that... I would not go back."<sup>103</sup> Additionally, Tess was frustrated with the lack of response from her contacts at the state rehabilitation agency,<sup>104</sup> and she was furious with the disability services department of her university for their mismanagement of the course and testing accommodations to which she was legally entitled.<sup>105</sup>

**Safety and security.** A less frequent subtheme, but one that was discussed by all participants, was the extent to which support systems provided (or failed to provide) safety and security, with direct implications for QOL. Many of the participants shared having taken various self-defense or martial arts classes. For Brianne, circumstances while she was living at home had resulted in her feeling less safe and in need of better ways to protect herself.<sup>106</sup> She discussed a personal safety course offered at her rehabilitation center,

... it was something I took when I first came here, taught us how to, like somebody was trying to grab us or something, taught us how to get out of the grab or, because you know people are crazy these days, you never know what could happen, so it just taught us how to get out as a blind individual or whatever without hurting them, and pretty much taught us how to, like if

somebody at a bus stop continuously asks us for money, just taught us how to deal with that, it was a pretty good class, something that I needed that's for sure.<sup>107</sup>

Tess also experienced threats to her personal security when she was bullied in middle and high school, but shared some of the support systems she has accessed to protect herself in the future:

I took karate when I was really small, like middle school, because people were bullying me every day. I had to protect myself somehow. So, if somebody came up and ever tried to do anything aggressive, I could respond. And I'm sure [my dog guide] probably would too, even though she's not trained. I mean, the biggest question I get asked by people is, "Does your dog bite?" Usually I will say "No." But if it's a shady character that I'm not comfortable with, I'll say, "Well, you know what? Don't mess with me and you don't need to worry about that." Hey, it works. I mean, you know? But she's not trained.<sup>108</sup>

**Other codes.** The above-mentioned subthemes were part of the life experiences described by all participants; however, during my analysis, I applied a range of codes to text segments of interest and discovered some topics or concepts which were only reported by a few participants. Some of these codes or topics represented especially important aspects of QOL for certain participants or resonated with my experiences as a TVI. In addition to the subthemes which all participants discussed, these additional topics also served to better describe the major theme of an external system of supports and its relevance to QOL.

One of these less-reported codes for the major theme of external system of supports is "faith," including religious traditions and communities. For Tess, her faith and attendance at a Christian church were a central theme throughout all three interviews. She stated, "My faith is extremely important to me. I'm a Christian and, I mean that's the most important thing in my life."<sup>109</sup> Darik described having a

relationship with his church growing up which left him feeling conflicted about biblical stories of “Jesus healing the blind man.” Later, at the university, misguided Christians sometimes approached him with offers to pray that he would be healed, to which he responds, “Have you asked me if I wanted to be healed?”<sup>110</sup>

Another important code was “having my own home.” All of the participants were looking to the future and considering what their lives would be like, and several of them discussed the benefits of having a place of their own. In having her own place, away from her family, Brianne said, “I’m making my own decisions. I’m doing things on my own. I don’t have someone moving things, when they know I can’t get to them if they move it.”<sup>111</sup> In the future, Janessa wished to “hopefully... live in a house instead of an apartment. Because I’m just living in apartments now just to get me started, started off. So hopefully I’ll have a house.”<sup>112</sup> Martin was less concerned with a house over an apartment, but still saw having his own place to stay as a sign of things going well in his life.<sup>113</sup> Having a place of one’s own is an external support which offers privacy (another code which I noted on some transcripts<sup>114</sup>) and is directly connected to the major theme of independence.

## **Experiences**

The second major theme which was well demonstrated in all transcripts was “experiences.” I defined this theme as events and activities in which people participate; as opposed to other major themes from my findings which relate either to people, systems, personal attributes, or dispositions. Whether good or bad, experiences shape participants’ QOL and may – to varying extents – be seen as defining aspects of high or low QOL.

Having experiences, and the extent to which a person benefits from experiences, are certainly connected to other major QOL themes from this study. *Independence* requires having had supported experiences and leads to new experiences. Many experiences involve or are impacted by the *external support system*, which can both inhibit and improve access to experiences. Likewise, having experiences may lead someone towards or away from other types of supports. An *internal support system* provides (or fails to provide) motivation and confidence to engage in experiences, and those experiences may bolster or damage the internal supports. For people who are blind or visually impaired, experiences often involve some level of *interdependence*, particularly for experiences in environments designed for visual access. Prior experiences with seeking assistance or relying on others may impact an individual's inclination to be interdependent in the future. Finally, accessing new experiences both depends upon and leads to the acquisition of *knowledge and skills*.

As with the major theme of external support system, participants did not explicitly address the impact of “experiences” in general on their QOL. As a consequence of my phenomenological approach to this study, my interview protocol contained questions that prompted participants to discuss “times in their life,” frequently leading to descriptions of experiences (as intended by the purpose of the study). To identify subthemes in the major theme of experiences, I focused on the reasons participants’ sought experiences (doing something meaningful, going places, being in motion) or the benefits gained from the experiences (outlet, making mistakes). With the exception of the subtheme “being in motion,” which was

identified by five participants but not by Brianne, all the subthemes were supported in the transcripts for all six participants. Table 4.3 details the frequency of text-segments for each of these subthemes in each participant's transcripts; again, the within-participant variation in subthemes is telling of what qualities and aspects experiences were significant to each participant.

Table 4.3

*Frequency of Text Segments Connected with Experiences Subthemes for Each Participant*

Subtheme	Alex	Brianne	Darik	Martin	Janessa	Tess	Total
Doing something meaningful	<u>35</u>	<u>19</u>	<u>36</u>	<u>28</u>	<u>29</u>	<u>84</u>	<b>231</b>
Going places	19	8	12	15	18	20	<b>92</b>
Outlet	8	3	13	1	2	14	<b>41</b>
Making mistakes	4	2	6	1	3	2	<b>18</b>
Being in motion	1	0	2	1	6	2	<b>12</b>
Other	13	3	8	6	1	3	<b>34</b>
Total text segments	80	35	77	52	59	125	<b>428</b>

*Note:* Underlining indicates the subtheme(s) most frequently reported for each participant.

**Doing something meaningful.** For all participants, the most frequently coded subtheme in the interviews was “doing something meaningful.” I arrived at this subtheme based upon the many and various experiences in which participants’ described seeking out or hoping to pursue experiences of personal significance, including experiences of productivity, personal challenge, giving back to others, defying expectations, and achieving goals. The phrase “do something meaningful” is

directly from Tess, who shared that her rationale for wise financial planning (a good indicator of one's personal priorities), is "I would rather save up my money and do something meaningful with it."<sup>115</sup> How each participant wants to have meaningful experiences certainly varies.

All participants mentioned being productive and/or employment as a meaningful part of their current or future lives. To be clear, productivity does not necessarily imply that the participants wanted traditional employment, as Alex indicated,

We're making more and more jobs because money is such a motivator when the jobs are no longer necessary and people could be pursuing things that they are actually interested in, in my case traveling. So I don't see that it's necessary. I don't buy into the traditional view that you have to work in order to be a productive member of society.<sup>116</sup>

Darik did give greater emphasis to employment as part of productivity, saying, "What NPR showed me is that there are people who are interested in many things. But they channeled their interests. They can channel it into a productive life. They made their curiosity work for them."<sup>117</sup>

All participants discussed clear financial motivations for having jobs. For Martin and Janessa, QOL was strongly associated with productivity and employment. Even if she won one million dollars, Janessa said that she would still want to work both for enjoyment and for financial security. She explained,

... Because I know that the way that I go, it will get spent. [laugh] So I'll need that job to still get me through. Because although I'm paying off the house note, maybe a couple bills here and there, it's still, it won't cover all of it if it was gone... Some people... work just because, just for the money but they don't like it. I want to be able to enjoy going to work every day. ...I'm willing to put in more than what I have to, and because when you put in more than you have to then, some people might look at that and then you could get like a promotion.<sup>118</sup>



With regards to the situation of other individuals who are blind who may choose to stay at home and not work, Martin felt that he could not understand and would not be satisfied with a non-productive life. He said,

It's just a distraction. Because I think that if you were to just stay home and just be on the computer all day and watching movies and all that, it will get boring after a while, ... and just stuff like that, it gets old after a while just being home. And, you know, people have to go out there and, and also you get the benefit of knowing that you've earned the money. By, you know, putting effort into your work.<sup>119</sup>

For Tess, meaningful experiences were often connected both to pursuing her personal passions (especially foreign languages) and to giving back to others. Discussing how her favorite subjects in school connected with her academic and career activities and the experiences she hopes to pursue, Tess said,

I loved language arts, foreign language, history, you know, world geography. Stuff like that. I think those were probably my favorites... growing up. Which is why I decided to become a language major because, that's, I mean, you know, what you're supposed to do in your life by the gifts God gives you. And I know languages – I always knew languages was one of my gifts. So I knew, there's no question about what I was going to do. I knew that that's what I loved the most and was the most passionate about, so I decided, you know, I want to do that and enjoy that rest of my life and work with that. It's something I'm good at and I love.<sup>120</sup>

Tess also indicated a desire to mentor novice dog guide users and to integrate her language skills with her faith as a missionary overseas,<sup>121</sup> with direct implications for how she perceived her future QOL:

I want to spend a lot of my life reaching out and helping other people... It brings me great pleasure to study languages, to talk to people in other cultures, and to help people and make people's lives better. It makes me happy!<sup>122</sup>

Brianne also sought meaningful experiences and employment which would allow her to give back to others who shared some of her experiences. She shared that, if not for perceived difficulties with job access, training, and transportation, she would

have pursued a career as a social worker, and she was still considering ways to realize that goal. Brianne explained her motivation:

I love helping people, like children who have either been neglected, abused or whatever the case may be, because I have been through some of that, too. So I don't want, I want to be able to help other children before they grow up and are emotionally scarred... So, just I am helpful and, caring person, that's part of it.<sup>123</sup>

**Going places.** Another subtheme of experiences, and a rationale for all participants for having experiences was simply the desire to “go places.” As previously discussed, lack of transportation and the frequent requirement of relying on others to go places often limits the ability of people who are blind to travel, even within their own communities.

Alex, Janessa, and Martin discussed a rationale for going places which is perhaps unique to people who are blind, the idea of intentionally “getting lost.”<sup>124</sup> For these participants, “getting lost” meant taking off, usually independently or with friends who are blind, with the intention of getting disoriented, resulting in an enjoyable challenge of finding their way back home. For Martin and Janessa, it was not clear that they were especially intentional about getting lost, as much as they did not mind if the “getting lost” experience occurred; however, for Alex, he regularly, intentionally set off with no particular destination in mind, looking forward to whatever he might encounter. He proudly described following a park trail that was no longer in use, sliding down into a gully, and then navigating his way back home.<sup>125</sup>

Describing a more positive experience of getting lost, he said,

I guess randomly I got lost in [city] coming back from seeing my girlfriend. And I ended up in a mall, sort of plaza thing. I had no idea where I was, I just knew I was in a mall. And I decided, “All right well, I guess I’m lost for the day. I’m going to go get some McDonald’s.” So I went and got a drink and

some food, and I sat down at a table. I was just sitting there, and some guy came over and sat down in front of me and started talking to me. He realized I was lost. And he turned out to be just this really, really fascinating man. He's in seminary school, but he was also studying logic. We had a really, really fascinating debate on religion for about two hours. He drove me back to the bus place. And then I gave him my number, and I meet up with him every couple weeks. Whenever I can. And we sit there and debate God.<sup>126</sup>

This “getting lost” notion is similar to another rationale for going places, which is simply to explore or have an adventure. Not surprisingly, Alex shared the most “adventure stories” of the participants, including cave diving and jumping off of cliffs,<sup>127</sup> but other participants also expressed a desire for discovery and exploration. Darik rationalized his decision to attend an honors reception that was mainly with premedical students by saying, “Then I thought to myself, ‘It’s off the beaten path. So go.’ And I went and I enjoyed myself and met new people, had new conversations, new experiences.”<sup>128</sup>

All of the participants expressed a desire to travel for the enjoyment of visiting different places. For Brianne, who had only ever traveled to two states, the opportunity of spending the summer vacationing in a new state was weighing heavily against her advisor’s suggestion that she enter another rehabilitation program to learn job skills.<sup>129</sup> Martin enjoyed regular trips with his family to their ranch outside of the United States,<sup>130</sup> but he also expressed a desire to go to Japan and South Korea, saying, “Ever since I was younger, I’ve always loved to watch anime... and, I always liked to listen to the Japanese audio content, because, I don’t know, I just always found it really interesting, the culture.”<sup>131</sup>

**Outlet.** Another subtheme of experiences is the desire of experiences which provide an outlet, for energy, stress or personal creativity. Every participant discussed

engaging in some sort of physical activity or exercise program, and many emphasized a desire to stay active. Janessa explained that she has tried out a variety of sports-related experiences, including being on her high-school step team, saying, “Although I didn’t do sports in high school, and in middle school I did shot-put. And I wasn’t really just into sports like that. Mostly, ‘Oh, I want to do this.’ And anything that kept me active. I’d try.”<sup>132</sup>

Alex and Darik were both involved in martial arts programs,<sup>133</sup> with Alex adding, “[I’m] interested in sort of trying to take what I can from different arts and fuse them into a system that works for blind individuals. And so I’ve sort of started formulating my own rough sketch of a martial art.”<sup>134</sup>

Brianne found an outlet for stress and worries through participating in a pottery class at her rehabilitation center. She said,

Pottery also helps. It helps relieve stress, because of all the rolling and pounding that you have to do.... [and] when it's 75 degrees outside and you can just walk, I'm good with that too. And listening to music helps a little, not much but it does.<sup>135</sup>

Tess’s primary “outlet” experience, without question, was football and sporting events. She described her emotional attachment to watching the sport and attending games, saying,

I’m a huge football fan. Football, God used football to help save my life. Football gave me something to smile about every day, and I could tell you stories. My dad and I, we’ve gone to ball games every year for like the last 12 years, and I got to meet some of my favorite football players, and shake their hands... and it gave me hope. I could have a reason to smile and keep my head up. And like, in the fall, three hours on Sunday were my three hours of peace and happiness. It didn’t matter if we won or lost, I could have my three hours of joy. It was my outlet. Sports, to this day, I mean it’s my outlet.<sup>136</sup>

**Making mistakes.** Another aspect of experiences, although not one

purposefully sought by most people, is the opportunity to make mistakes and to be influenced by them – for better or worse. This subtheme was not as common as participants’ descriptions of more positive experiences; nonetheless it was mentioned by all six individuals. Alex and Darik had both shared an awareness that their personal quests for independence have not always been for the best.<sup>137</sup> Alex explained, “The independence streak in me kind of ensures that I don’t rely on people as much as I probably should.”<sup>138</sup> Likewise, Tess learned a hard lesson about not seeking help during her freshman year at her university:

To the point, actually where I failed three out of four classes my second semester in college. I’m just being straight up. I did. I made some stupid decisions. I gave up mid-semester, and I didn’t tell anyone that I needed, I didn’t tell anyone how bad a shape I was in. I mean, like I said, it was stupid. You know, I mean, freshman, they’re dumb.<sup>139</sup>

At the more day-to-day level, Martin confessed to hesitancy in social situations, describing, “Socially, you know the whole transportation aspect of having to go out and walking, sometimes I take a wrong turn and I’m like, oh darn. That’s not a good thing.”<sup>140</sup>

**Being in motion.** All participants except Brianne expressed in some way that they sought experiences to keep themselves active or “in motion,” as opposed to boredom or stagnation. For Darik, who confessed, “I don’t like static-ness,”<sup>141</sup> being in motion was itself a reason for traveling. He said, “It’s just, the desire to be moving and be alive is brought to the forefront when I’m traveling.”<sup>142</sup>

Sometimes the visually-oriented nature of public spaces and social activities can lead to stagnation and boredom for persons with visual impairments. Alex expressed that “you know, there’s only so much you can do to a museum in order to

make it interesting. It's still going to be boring.”<sup>143</sup>

**Other codes.** Under the major theme of experiences, a few additional codes appeared in some transcripts but were not found consistently across participants. These were the somewhat opposing concepts of “a routine life” and “novelty.”

Tess admired older dog guide users who were married with jobs, living routine lives,<sup>144</sup> and Martin stated, “Living, you know, a routine life – that's just my dream.”<sup>145</sup> In contrast, Alex particularly disliked routine, although he recognized that he may become more comfortable with it as he gets older. With respect to the repetition of university life, he stated,

I think anything, if you do it enough, it just becomes repetitive. And, you know, you're only going to live for 70-plus years. What's the point of wasting four of those doing something repetitive? I don't know... Maybe when I'm more mature, more wise, if you will. Maybe I'll find something but, at the moment I don't know.<sup>146</sup>

### **Interdependence**

The third major theme in my study of QOL as experienced by these six young adults is the notion of “interdependence.” I defined this theme as those social decisions, interactions, and dispositions, both of the participants and of the people they interact with, which comprise the person's overall experience of being inter-reliant with others. As with the external support system, the theme of interdependence is especially relevant to persons who are blind and living in a visually oriented society. Even the most independent participants in this study relied on other people and institutions for information, financial support, advice, disability-specific accommodations, and transportation, and their success or failure with interdependence had important consequences for their QOL.

The interconnectivity of interdependence with *external support system* and *experiences* has been previously discussed. Interdependence is also related (sometimes conversely) with *independence*, although the two are not opposites. To live in a community, whether sighted or blind, we must all be able to balance both taking responsibility for ourselves and sharing our burdens and gifts with others. An example of the interconnection of these two themes is that failing to maintain a minimum level of independence can lead to isolation, thus impacting one's ability to interact with others and be interdependent. Likewise, the major theme *internal support system* depends upon and influences a person's interdependence. Working with others requires motivation and confidence, and can also be demotivating and defeating. Finally, interdependence is required to access knowledge and skills through others (parents, educators, etc.), and possessing knowledge and skills enables interdependence by equipping people with intellectual capital and abilities for sharing with others.

The term interdependence did not appear in any of the transcripts; however I inferred it from participants' discussion of their successes and struggles in social experiences. Five subthemes captured all of the codes under the major theme of interdependence, and I identified these subthemes based upon the nature of the experiences with which each is associated: help-seeking scenarios, generic social situations, circumstances where others are insensitive, situations specifically involving working with the sighted world, and experiences of acceptance and inclusion. Table 4.4 provides the frequencies of each subtheme for each participant. The within-participant variations in subthemes provide insights as to which areas of

interdependence were significant to each participant in his/her described experience of QOL.

Table 4.4

*Frequency of Text Segments Connected with Interdependence Subthemes for Each Participant*

Subtheme	Alex	Brianne	Darik	Martin	Janessa	Tess	Total
Accepting help	<u>18</u>	<u>13</u>	17	<u>18</u>	<u>19</u>	<u>47</u>	<b>132</b>
Being social	14	11	<u>28</u>	13	14	38	<b>118</b>
Insensitivity	4	7	8	4	4	26	<b>53</b>
Integrating with sighted people	10	2	11	5	4	9	<b>41</b>
Being accepted and included	8	3	6	1	4	14	<b>36</b>
Total text segments	54	36	70	41	45	134	<b>380</b>

*Note:* Underlining indicates the subtheme(s) most frequently reported for each participant.

**Accepting help.** Participants expressed varying levels of comfort and experience with accepting help from others. Help and the decisions to accept or refuse it could both improve or decrease QOL. For example, Alex – although very independent with respect to making decisions – was especially willing to accept help from others to achieve his goals. He described how being open to help from others aided him in overcoming barriers to transportation:

... Most people are willing, they see a blind person, they go, often, “Well obviously there is no public transit, so I’m going to offer them to help.” And sometimes they’re willing to give you a ride; sometimes they’re willing to just help you out in any number of ways.<sup>147</sup>

Janessa described her more passive acceptance of assistance when she was in high



school, saying “I would just let people help because I know that’s what some people wanted to do, they want to help,”<sup>148</sup> but later noted, “... once I actually got out here in the real world, I finally realized. I was like, no, people they try to help too much.”<sup>149</sup>

Darik also expressed recognition of the need to be interdependent but emphasized the importance of being able to choose if and when to accept assistance:

... And I understand that we all depend on one another to some degree, that’s fine. But when that choice of how much you depend on someone else is taken away from you, without – I don’t care how harsh your circumstances are – that’s just, it’s not good. You know that saying about being in a well-appointed cage, or a well-appointed prison?<sup>150</sup>

Alex’s willingness to accept rides from friendly strangers perhaps stemmed from his positive experiences and his confidence in his ability to travel whether or not help was provided. Participants often resisted or reluctantly accepted help when they were given no alternatives or when the offer of help put limits on their options and schedule, which was a common situation with respect to transportation. Martin shared,

The unfortunate thing is, whenever you’re blind, you’re going to have to rely on a lot of people for a lot of things. Some of them may include transportation... You’re going to have to adjust to their schedule if you need those services, like getting driven to work, to and from work. You know you’re also going to have to make sure to stay in good communication with that person. But then again you know it beats taking a bus.<sup>151</sup>

Most participants mentioned trust as a factor impacting their willingness to accept help; lack of trust was a reason to stop accepting help and to take matters into their own hands. When she lost trust in her university’s disability services department, Tess stopped seeking most of the types of assistance she once relied upon. She explained,

Everything went south... It became, to the point, where I no longer asked them to do anything for me, and I no longer trusted them. Because they would tell me things and not do them. And lie. And they put me in, they would, you

know. Lie to me, basically, tell me everything's fine. No. It's not. You know. So, basically I just, at some point, just started handling accommodations on my own. Rather than rely on them, because they couldn't get the job done. You know. I handled it how I wanted to... I did what I had to do. I, after the, probably first half or more of my junior year... pretty much after that I knew I could no longer trust and count on my disability services to do anything for me.<sup>152</sup>

Walking away from unhealthy, interdependent situations, thus refusing further help was especially relevant to Tess, who advised, "Sometimes people will tell you, 'Don't ever walk away, don't ever give up. If you walk away, you are giving up.' But sometimes walking away is not giving up. It's the best way to deal with it."<sup>153</sup> Darik avoided a business which was not accepting his dog guide,<sup>154</sup> and Martin explained that he would work with others to help make situations accessible, but "...if it's not possible, then I just won't go near that particular thing."<sup>155</sup>

Participants' positive and negative feelings about accepting help also affected their attitude towards their external support system, particularly their families. Brianne was especially proud of herself for "Taking control and getting away from having to depend on my mom, and coming here to become independent of her."<sup>156</sup> For Tess, living at home meant mixed feelings of guilt and appreciation for needing help from her mom and dad.<sup>157</sup>

**Being social.** In addition to help seeking and refusal, participants' experiences often connected to a subtheme of "being social," and the consequences of social and anti-social behavior for interdependence and QOL. Being social is an interdependent function, requiring interaction between a person and a member of his/her society. For most people and situations being social or sociable increases the chances of encountering offers of assistance and leads to greater satisfaction and a sense of

inclusion. Darik clearly conveyed this relationship when he described the “tough time” he experienced during adolescence when his hearing loss became more profound:

For me, it was not the blindness that stood out, it’s just the hearing. And this became even more pronounced in middle school, when the social aspect of things became more important. I was still at the top of my game academically. Whenever it came to talking with teachers I was fine. But when it came to the social interactions with peers, because I could never trust what my ears were hearing, well, I felt more like withdrawing from that social context. But, it was a terrible thing really, because that’s what middle school and high school are about. As much as academics, it’s about the social interactions. And very much I retreated behind my academics... I was able to convince myself that academics were fun, could substitute for social interaction. But sometimes I couldn’t pretend that.<sup>158</sup>

All of the female participants (and none of the male participants) described that being shy in social situations kept them from experiences that they might have otherwise benefitted from or enjoyed. Tess and Janessa considered shyness to be a part of their past rather than their future; however shyness remained a present challenge for Brianne.<sup>159</sup>

Friendships were a key component of all participants’ social connections. In addition to the computer science coursework at his future university, Martin was particularly looking forward to “... building friendships with other people, socializing of course. That whole socializing aspect.”<sup>160</sup> Tess explained the importance of finding friends who appreciated her as a person, rather than pitying her or seeing her as a “service project.” She said,

When somebody becomes your friend because of who you are as a person and who they are as a person, and you connect, they are going to be there for you for a long, long time... they are the kind of person that will comment on or like your Facebook stuff, you always kind of keep tabs on. If you ever need anything, they’ll pray for you. ...People that are your friends because they feel sorry for you, and they feel sorry for “the poor blind person you need a friend,” they are the ones that will walk away when it’s no longer convenient for them to be your friend. ...Because, their friendship is not borne out of they like you

as a person. They want to know me as a person. It's borne out of feeling sorry for someone and feeling like, "Oh, poor so and so. Poor disabled person. You need a friend"... And they'll be out of your life quicker than you can blink. ...Because you were just a project for them.<sup>161</sup>

Friends provide useful, honest feedback, as Darik experienced:

My friend and I went shopping... And I was checking out. There is a girl behind the register, and she engaged me in conversation. And my friend, when we were back in the car, he chastised me and said, "Dude! You need to speak up when you are talking to people... Because when you speak softly, then they are going to speak softly, and you can't hear them. And plus, you need to, if you can't hear them, you need to indicate your hearing aids or something."<sup>162</sup>

In addition to friendships, participants sought less personal, social connections with peers and older adults. Darik's additional hearing impairment further associated him with adults and distanced him from his peers. He shared,

...the thing about my decision-making process is that it requires a lot of information, which requires a lot of contact with specific people... Early on, my parents and I – of course because I was usually the only blind person at a school, in a class, in a program – we had to meet with higher ups... So I became very used to early on talking to higher-up people. In fact, to some degree I was more comfortable talking to the teacher of a class than to my classmates. So, and it was from these teachers that I would get a lot of inside information to make my decisions... Nowadays it's all about networking with your peers. Well, to some degree I still have difficulty networking with people my own age, more so than I do walking into a room and networking with someone much older than myself.<sup>163</sup>

When Alex was in middle school and discovered the sport of goal ball, he worked with his O&M specialist to start a youth league in his area.<sup>164</sup> Later as a young adult, he continued to keep in touch with the vision-specialist instructors from his K-12 experience, seeking (although not necessarily heeding) their advice about his upcoming travel plans.<sup>165</sup>

Additionally, for participants, experiences of "being social" sometimes just involved having someone with whom to talk. Brianne described the value of trained

counselors for discussing emotional concerns,<sup>166</sup> while Janessa expressed how much she missed the long phone conversations she used to have with her adult sister before her sister's working hours changed.<sup>167</sup>

**Insensitivity.** For all participants, experiences of insensitivity were an unwelcome but familiar part of their interdependent relationships; many such experiences have already been described as they connected with other themes and subthemes. The insensitivity subtheme involved uncomfortable experiences resulting from others' perceptions of blindness, including misconceptions and intended and unintended exclusion, and intolerance. As a child, Darik experienced unsolicited, ill-informed "help" from what he termed "the 'hurricane people,' [who] ...grab you and take you places."<sup>168</sup> Tess revealed a host of insensitive questions she used to be asked by strangers before she received her dog guide, including "What's wrong with you? Why were you born that way? Why does your eye look weird? What's your problem? Is anything else wrong with you?"<sup>169</sup> These experiences certainly had negative effects on participants' inclination to ask for help and socialize; additionally the subtheme of insensitivity connected with themes of independence (which enabled students to address or see beyond stereotypical attitudes) and knowledge and skills (such as the strategies taught at the rehabilitation center and dog guide schools for refusing unwanted help). Tess described how experiences of insensitivity helped her develop a more confident, assertive way of responding to frustrations:

And I think, some of it, too, comes from the fact that I've been told, "No," so many times in life. Especially lately, you know, from a university, from somebody. You know, "You can't do that," or "We are not going to accommodate," or "You just can't do that," or "Blind people can't do that," or whatever. No! Suck it. I can.<sup>170</sup>

Tess and Darik both described feeling responsible for correcting misconceptions and confronting stereotypes. For Tess, this ranged from letting her local cinema know that the sound-amplifying device that provides greater access to Deaf movie-goers was not the same as video description<sup>171</sup> to advocating that TVI's and others should respect students' decisions to walk away (as opposed to make a scene or file a law suit) in the face of some frustrations.<sup>172</sup>

Some insensitivity was less direct and occurred in the form of exclusion. Such experiences were memorable and distressing for Brianne. As a child, she loved to swim but felt isolated when at the pool or the lake with her family. Brianne said.

That's another thing that was one of the best times; we would go to the lake and just hang out. I mean, in a way. Yeah, I would be kind of boring, because I get left out, ... but I would just try to enjoy it the best I could, because I love to swim.<sup>173</sup>

With regards to friends, Brianne also expressed, “for reasons unknown to me they would all just fade away and hang out with my sister more. She was the popular one and everybody loved her. I mean she wasn't popular, but everybody loved her.”<sup>174</sup>

Martin also described exclusion, particularly from online multi-player gaming networks that effectively excluded him because of his disability. He said

Sometimes I get these feelings of being left out, as a blind individual. Because I like to participate in activities that require kind of sight to accomplish them. ...I like to do online gaming, and ...a lot of vision is required to do some of the, to do most of the stuff on there. But you know I like to challenge myself, but at the same time I kind of feel, oh man I can't really go, or I can't really do, or I can't really go to my full potential because of my blindness. And, you know, that kind of frustrates me a bit sometimes.<sup>175</sup>

**Integrating with sighted people.** A fourth, significant subtheme within interdependence involved participants' attempts and experiences interacting specifically with sighted people. The title of this subtheme came from Alex, who

expressed appreciation for his parents' encouragement to "...integrate with the sighted community, which ... I think it's key, I don't think it's always emphasized enough.

Instead of segregating oneself..."<sup>176</sup>

While *accepting help*, *being social*, and *insensitivity* subthemes potentially involved interdependence with both people who are sighted and those who are blind/visually impaired, the unique experiences that arose from interdepending across the "blindness-sighted" divide were reported by all participants and worthy of their own consideration.

Alex also partially credited his (sighted) brother and sister for his resilience and courage, explaining:

... They were better than average siblings. They tried to include me a lot, and they did a lot to make sure that I was – like, my brother would wrestle with me pretty much every day... – because a lot of blind children don't do things like that. And so they end up being, like, rigid in some ways, and have a fear. But I couldn't remain rigid or have a fear of anything because my brother... threw me down the stairs. [laugh] So, in a sort of violent way, my siblings were very good at making sure I was included, making sure I was just brought up in a very tolerant, integrated way.<sup>177</sup>

Both Martin and Janessa shared that being fully included at a public school was beneficial in that they could interact with sighted peers.<sup>178</sup> Janessa explained how she received some extra attention and teaching opportunities:

I would say, knowing how to be around sighted people. [Students who are blind] would have... more opportunities to teach other people about blindness. Because that's what I had to do. I had to play like the public speaker for some things, and it was good because I was like, "Oh this is all about me." No... I was like, "This is good, because people come up to me with questions, and I can tell them what it's like or even possibly teach them or show them." Some sighted people, all my sighted friends they wanted to learn braille, and I taught them the basics of braille. Some even wanted to learn like how, what it's like to use a cane. And I taught them a little bit about that too. It just depends, but you just get the feeling like it's all, not just to be like things are all about you, but "Oh, people recognize me!" And you get a chance to teach people.<sup>179</sup>

For all participants, their success or failure in interdependence with sighted people seemed to be a crucial element of their future success in pursuing employment, travel, and other goals.

**Being accepted and included.** This final subtheme for *interdependence* involves the beneficial nature of being incorporated and immersed as an equally valued individual within a social group. In some ways, this is the opposite of the previously described subtheme, *insensitivity*, which involved exclusion and an over-emphasis on stereotypical, perceived notions of blind people as less valuable or less capable. Darik provided an excellent image of being accepted and included during his elementary school years:

Elementary school? No. No difficulties, no toughness, never. A breeze. Academically and I would say socially. Why? Because, yes I was blind, and yes, I was losing my hearing. But it wasn't – the hearing loss wasn't yet to a very significant extent. And frankly I think children are better at dealing with disabilities and their peers than older people are. Children, they notice something; they react to it, as they will. Sometimes good and sometimes not. You know? But then they move on. Like, "He's blind. Cool, he's blind," and they move on, and they innovate very, very, very easily. Their minds aren't set on how things should be. So, they are able to be more imaginative and creative when it comes to inclusion. Great!<sup>180</sup>

After Tess received her dog guide, she described feeling "...like people recognized me as an equal peer, and as a whole, complete individual,"<sup>181</sup> rather than focusing on – and ostracizing her because of – her disability.

Importantly, being accepted and included connected to participants' external support systems. For Brianne, who did not feel supported at home or amongst her peers, acceptance was an aspiration. In discussing accepting peers, she said, "Those people if I ever found any would be really awesome."<sup>182</sup>



## **Independence**

The fourth major theme that emerged from my analysis is one of the first that came to my mind at the beginning of the study. Independence is a major part of the Expanded Core Curriculum (ECC) for students with visual impairments (the curricular areas emphasized by TVI's and O&M specialists in K-12 schools). Teachers focus on independent living, independent travel, independence in academic coursework, independence with technology, etc. (American Foundation for the Blind, 2014). Likewise, special education law emphasizes the "least restrictive" (in other-words "most independent") environment. In identifying this topic as a major theme, I arrived at a definition of independence which involves actions, experiences, and attitudes of the participants which promoted or inhibited their direction of their own lives.

Each participant explicitly and implicitly addressed the idea of independence multiple times during the interviews. Three subthemes captured all of the codes under the major theme of independence, and I identified these subthemes in association with participants' objectives for acting independently— self-advocacy, self-determination, and self-reliance. Table 4.5 provides the frequencies of each subtheme for each participant. Within-participant variations in subthemes provide insights as to which aspects of independence were most significant to each participant.

Table 4.5

*Frequency of Text Segments Connected with Independence Subthemes for Each Participant*

Subtheme	Alex	Brianne	Darik	Martin	Janessa	Tess	Total
Self-determination	<u>22</u>	<u>10</u>	<u>16</u>	9	8	<u>18</u>	<b>83</b>
Self-reliance	13	5	11	8	<u>12</u>	13	<b>62</b>
Self-advocacy	6	1	<u>16</u>	8	8	11	<b>50</b>
Independence (no subtheme)	8	6	7	7	3	12	<b>43</b>
Total text segments	49	22	50	32	31	54	<b>238</b>

*Note:* Underlining indicates the subtheme(s) most frequently reported for each participant.

**Self-determination.** The freedom to make decisions for oneself was a major subtheme of independence. For participants, self-determination required both having options to choose from and being permitted to choose. Discussing his work advocating independence to other people with visual impairments, Alex said,

If you're independent you can make your own choices. The way I see it is that you can advocate all day long about very particular things, about "You should really use O&M skills," or, "You should really learn braille," or things like that. And that may be true. Some of those things are great. But they're also subjective; they're also conducive to that individual making that choice. I feel if you advocate independence and allow blind people to make the choice for themselves, then you will have much more informed and much more culturally aware blind people who are capable of integrating with the sighted community, as opposed to segregating themselves and having the perception that they must be different, because it's not necessarily true.<sup>183</sup>

TVI's often describe students with visual impairments who are not permitted to make decisions for themselves as lapsing into a state of "learned helplessness," where the non-self-determined child or young adult ceases to try to do things for himself/herself.

When others – whether parents, teachers, or peers – directly or indirectly imposed

limitations or interfered with this decision making, the participants expressed frustration. Darik described how having roommates with different habits and priorities prevented him from organizing his life as he would have liked, saying,

In terms of rooming in a college situation, I just don't like it. ...I hate going to cook something and finding the dishes, pots and pans – most of which I supplied – in the sink for a week or two, uncleaned. You know? Residue left on the stove so that when I do get a chance to cook, the food I'm cooking tries to burn itself, or there is smoke in the air because the stove isn't clean. And I even hate, much more, wanting to put some vegetables or something in the fridge and finding it stuffed full with beer and pizza. ...I prefer to be able to prioritize what I want to prioritize within my space. In a roommate situation, you have essentially a clash of priorities. If they like partying, if they like beer, if they like pizza, that's what's going to be in your fridge. That's the noise you are going to hear. Me, I like exercise, I like homework, I like occasional, you know, music or books or whatever. And I have to eke out my little space in my room, which happens to be very thin walled. So, it's not my thing.<sup>184</sup>

In another decision-making scenario, accessibility limitations inherent in commonly used software restricted Martin's choice of screen reading software, thus denying him alternatives and leading him to feel less independent despite his technology expertise.<sup>185</sup>

All participants also described positive experiences when they were able to independently make important choices which directly impacted their QOL. For Tess, this was never clearer than when she discussed deciding to apply for a dog guide and identifying the dog guide school she wanted to work with. She said,

[At first] I didn't fully understand the impact of a guide dog on someone's life. So, that was a decision that I sort of made by myself. I talked, I reached out and found a few guide dog handlers and asked them some questions. But, really it was, "You know? Really, maybe I should rethink this guide dog thing. I really need a dog. I need to do this. I need help." So I chose [guide dog program]... Having contact with my puppy raisers was a huge deal to me ...there are schools out there that don't allow you to have direct contact with your puppy raiser. I would never be okay with that. Other people are. It's their decision, their life. Me? No.<sup>186</sup>

**Self-reliance.** Another important subtheme of independence is the ability and opportunity to depend on oneself for routine needs as well as in challenging situations. Brianne described becoming self-reliant as a particular challenge which she viewed as directly connected to her visual impairment: "... as I was growing up, not knowing the skills that I'm learning now, to be able to be independent... I used to have to depend on my mom for every little thing, which I did not like it all."<sup>187</sup>

As with all young adults, becoming self-reliant has been a part of participants' transitions to adulthood, and participants exhibited varying comfort levels and desires for self-reliance. Alex did not mind relying on sighted assistance and counted on it during his adventures, but he preferred text-to-speech technology over human readers to assist him in his studies so that he could control the pace and direction of his access to information.<sup>188</sup> Similarly, he was not interested in having a dog guide, saying "I prefer to be able to control my own orientation, as opposed to relying on a dog. I don't distrust dogs, but I also don't really want to have a dog be my eyes, if you will."<sup>189</sup> Contrastingly, Darik happily accepted a new level of self-reliance that came with the responsibilities of caring for his dog guide, explaining,

In a way – a very, very, significant way, [it's] like having a kid...you know what it's like to have a sleepless night when your kid is sick. And when your dog is sick, it's the same thing. There was a meeting I was attending here... and the night, the week of that meeting, [the guide dog] had eaten something he shouldn't have, and the results were not very good for his stomach. ...I had to become emergency chair of that meeting; at the same time I got no sleep for two nights running because the dog had to go out constantly... and, you know, I now know what parents go through. The extremes of pride... and then the next minute super anger and disappointment... [R]esponsibility? It's something I accept with pleasure.

Looking to the future, Tess was especially concerned about finding employment so that she could cover her own expenses, move out from her parents' home and stop

receiving SSI. She said,

I know people who... are content with getting SSI and either living at home or getting SSI and living in Section 8 housing. And I'm not – I really don't want to become one of those people, and the fact that I might be on my way to becoming one of those people scares me... If you really need that for a season, in your life, okay, but, if that's all you're ever going to do, you know, I don't want that to become my life's end. So, that scares me. I really hope that I can find work and provide for myself, but, we'll see. I worry about that a lot.<sup>190</sup>

**Self-advocacy.** In addition to making their own decisions and being responsible for their own lives, participants also provided multiple examples of self-advocacy or speaking up for themselves as a part of their independence. Certainly, this subtheme is connected to knowledge and skills (knowing what to say and how to say it when self-advocating), the internal system of supports (being confident enough to speak up), and interdependence (negotiating situations with others through self-advocacy). Participants described a variety of successful and not-so-successful self-advocacy scenarios as well as how they found and continued to find their “voices” in order to speak for themselves.

All the participants in this study were their own legal guardians; this is not necessarily the case for young adults who are blind. When students turn 18, parents can apply to retain guardianship – in which case the parents would continue to make legal decisions and to receive SSI benefits on their behalves. To obtain her independence, Brianne had to confront her mother and advocate for herself. She said, “I had to tell her, I was like, I want to do this, and, pretty much, I can't have you making decisions for me for the rest of my life.”<sup>191</sup> Certainly this was not an easy confrontation for Brianne, and her self-advocacy resulted in both positive consequences (greater independence) and greater challenges (a strained relationship

with her mother).

Janessa explained how learning the “art” of subtle self-advocacy during a job search was crucial for people with visual impairments, particularly to overcome misconceptions about people with visual impairments during job interviews with mainstream employers. She said,

There are lots of challenges. Like, you know, you go in for an interview and the boss... is just sitting there thinking, “Oh my gosh. How are they going to do this? What are we going to do? What do they need from us?” And it’s much harder for them to get into it because the boss is looking at them that way... like no, you can’t do anything for them, can’t help them. But our job is to get the boss – like make a little joke or just lighten the boss up then go into details... that they don’t really need to assist you with much. You just need a little bit of help, and, you’re doing it just like the sighted people.<sup>192</sup>

Darik developed a self-advocacy routine in middle school for getting to know his professors and explaining his particular needs with respect to his visual and hearing impairments. He continued this same system in high school and college:

Email is one of the first things I do. I find them on the [university’s] website, get their email addresses, send them a nice, concise email introducing myself, telling them that I am deafblind, explaining to them what that means. Usually what I do – I don’t want to spell it all out to them in the email. I just give them the bare-bones in the email and say, “could we meet before the semester begins?” Or as early as possible, because a lot of this is best explained face-to-face. I mean, I can tell people “deafblind” until I am blue in the face via email, and they will have all kinds of misconceptions; so, it’s best for them to define what deafblind means in my case once they see me in person.<sup>193</sup>

## **Knowledge and Skills**

This fifth major theme encompassed particular types of information that participants possessed or actions they were able to perform. Often, participants described knowledge and skills that were as a result of education and learning (a subtheme of external support system), but the impact of their knowledge and skills extended well beyond the instructional experience.

Some of the subthemes I identified for this theme were similar to the categories of the Expanded Core Curriculum (ECC) – particular skills related to blindness – in which case I was influenced by my knowledge of the ECC in naming the subthemes (American Foundation for the Blind, 2014). Other subthemes involved general academic abilities of use to people with and without disabilities. Five subthemes (*orientation and mobility*, *braille*, *daily living skills*, *math*, and *career and college prep*) were discussed by all participants, and another (*writing*) was discussed by all except for Tess. Table 4.6 details the frequency of text-segments for each of these subthemes in each participant’s transcripts. The within-participant variations in subthemes were telling of the types of knowledge and skills which were significant to each participant’s prior experiences and future career goals.

Table 4.6

*Frequency of Text Segments Connected with Knowledge and Skills Subthemes for Each Participant*

Subtheme	Alex	Brianne	Darik	Martin	Janessa	Tess	Total
Orientation and mobility	<u>9</u>	3	<u>9</u>	4	3	<u>11</u>	<b>39</b>
Braille	3	5	6	<u>8</u>	2	5	<b>29</b>
Daily living skills	1	<u>8</u>	3	4	1	9	<b>26</b>
Math	2	5	1	7	1	4	<b>20</b>
Writing	8	3	2	3	4	0	<b>20</b>
Career and college preparation	1	3	6	1	<u>5</u>	2	<b>18</b>
Other	9	4	8	4	0	10	<b>35</b>
Total text segments	33	31	35	31	16	41	<b>187</b>

*Note:* Underlining indicates the subtheme(s) most frequently reported for each participant.

**Orientation and mobility.** All participants were fully, physically capable of walking through their environments; however, each one's total or almost complete blindness meant that he or she needed special techniques for orientation ("where am I and where do I want to go?") and mobility ("how do I get there?"), referred to in the field of visual impairments as "O&M." In the United States, these techniques are most commonly taught by a Certified Orientation and Mobility Specialist (COMS). In K-12 schools, O&M instruction was provided to all participants, generally starting at pre-school age at which time cane traveling techniques are first introduced. Later, students learn to navigate through buildings, cross streets, and utilize public transportation. Dog guide use is an additional subdivision of O&M which requires prior fluency with



cane travel.

At the time of the interviews, Brianne, Martin, and Janessa were all enrolled in post-secondary O&M courses as part of their transition programs, and they described a special emphasis on learning street travel and public transit.<sup>194</sup> Brianne described herself as a route-traveler. She struggled with memorizing the precise steps needed to get to particular destinations, and she was unlikely to travel to destinations independently until she had traveled with a partner several times and memorized the route. Her limited O&M skills had direct implications for where she could travel independently. She explained,

I was worked more with here [at the rehab center] than I was in high school. In high school it was just like maybe once a week for thirty minutes, or twice a week for thirty minutes, which does not help me very much... Street crossings, the route to... class at [community college] – I was working on the route from [rehab center] to [my apartment], in like September, well August. Which that, I spent three months on, but finally got it.... That's pretty much it. Just a bunch of route traveling.<sup>195</sup>

Her favorite place to visit, a local Mexican restaurant with live mariachis, required “a little bit of walking after you get off the bus, which,” she said, “I don't know the route for, so I'd have to go with somebody if I wanted to go.”<sup>196</sup>

All other participants expressed a greater mastery of O&M techniques, though Martin said that he would continue to seek out the help of a COMS when relocating to a university campus or another city.<sup>197</sup> For Alex, who described feeling confident with independent cane travel from a very early age, O&M skills were something he felt he could best teach himself or learn through experience. He said,

[A] lot of the O&M skills, I learned them but I didn't necessarily apply them until I got out into the real world and said, “Oh look, well I do need to use these.” Some things O&M can't teach you, sometimes. You know my O&M teacher would never have condoned crossing [a major interstate] as a

pedestrian... but it's necessary. I mean, I live on the other side of [a major interstate]... Unless I want to take the bus... which only runs every two hours, if I need to get somewhere, I have to cross... I think an O&M teacher would have shied away from it. They would have asked me to find an alternative route.<sup>198</sup>

**Braille.** Like O&M, reading and writing braille involves a unique set of skills which have limited practical use for those not connected to the field of blindness and visual impairments. All participants were proficient braille readers who used embossed braille and or computer braille displays to varying extents for accessing written information and communication. The young adults also described using braille less frequently after high school, especially given the improvements in screen reading technology. In fact, Alex admitted,

I haven't read braille in forever. Genuinely, braille, I don't use braille anymore at all. I think, I think braille has its place. I think children should learn it. However, I think it's, it's difficult to use in a very – in a technological setting because you have to have a braille display, otherwise you're printing off a bunch of braille paper which is so bulky and it takes up so much space. A braille display is another thing. Braille displays are, at the moment, on a technological level, incredibly delicate. They break so easily....drop it once, and it's done. [Laughs] It's just, you know, I think braille has its place but it's also, I think it's a little antiquated. ...I can read JAWS at 700 words per minute. There's no way I could ever do that with braille. It doesn't matter how good of a reader you are, you can't do it. You know, nonetheless, I think braille has its place.<sup>199</sup>

Martin, who participated in national advocacy efforts that emphasized the importance of braille for people with visual impairments, viewed braille as especially connected to QOL. He said,

A lot of blind people are starting to rely a lot on screen readers reading out their content to them, and you know that can sometimes be a bad thing because they won't be able to spell out certain words that they think are spelled a certain way, and the way that a screen reader announces them isn't always the way it's spelled. People are being directed more towards utilizing computers now than braille. Like I said, I can't emphasize how braille is important, so important.<sup>200</sup>

Being a braille reader and not a print reader frequently raised additional complications for the participants and their teachers and families. Darik gave a vivid picture of these difficulties, explaining:

For school ...we'd contact the publisher, talk to them and then have it brailled through the TVI office, or have it delivered if it was already there. For much of kindergarten through fifth grade, a lot of those books are just stock books that the state uses, so they tended to be ready and available. Middle school became a lot more problematic... and this is, again, where their innovation comes in. My father and mother would often draw on braille paper using pencils to make impressions in order to show me what a graph looked like or a shape looked like, because we didn't have the book. Even in high school – because this is a risk of taking off the beaten path subjects like, “What? A blind person is taking Anthropology? American History? Contemporary History?” – so, they wouldn't often have those books... So, my mom actually resorted to reading chapters of my Contemporary History book and recording it on tape. ...And even here we had some difficulties because, again, it's off the beaten path. Anthropology texts. A lot of time I was playing catch-up to my classmates because I'd fallen behind while waiting for a book, a chapter to be brailled.<sup>201</sup>

Stories like Darik's further demonstrate the connections between the theme of knowledge and skills and other themes and subthemes including education, equal access, self-determination, and interdependence.

**Daily living skills.** Depending on which participant I talked to, daily living skills were either viewed as unique techniques to be learned by people who are blind or basic tasks that all young adults ought to learn at home. Either way, being able to care for oneself and one's possessions was understood to be essential for leading a life of good quality.

Tess credited her mother, a TVI, for teaching her basic cooking skills, although she wanted to learn more. She also expressed,

I really want to learn home repair skills. I have a toolkit, but I don't know how to use it. Like, I don't know how to use a screwdriver or a hammer or whatever. If my blinds fall off my window, you know, my mini blinds fall down, I can't fix it. So, I definitely want to try to... learn some home repair

skills. Like basic, you know like dealing with curtains or dealing with things that might break. Screwing a light switch into a wall – I learned that the other day. That was fun. But you know, like some basic home maintenance type stuff. I definitely want to do better learning that.<sup>202</sup>

Brianne was concerned with learning shopping and budgeting so that she could live independently on a limited income,<sup>203</sup> and Martin was pleased with his success in learning to plan and prepare meals. He said,

We kind of go through this process of researching recipes, in the [transition program]... They'll tell us some of the advantages and disadvantages of those recipes as far as cooking with different utensils, different accessibility methods. And, you know, they'll give us suggestions on that, and then we go out and buy the groceries for those recipes, and then we just cook on our assigned days. It's pretty cool.<sup>204</sup>

Although Darik did credit the rehabilitation center for teaching him a few skills such as ironing,<sup>205</sup> he strongly believed that daily living skills were universally needed abilities which ought to be taught in the context of home and family. Darik explained,

[T]his is a pet peeve of mine... if a blind person knows how to perform certain independent living skills like wash their clothes, dress properly, tie their shoes, even shave, the automatic assumption or question is, "What school did you go to? What blind school taught you how to do this wonderful thing?" And that incenses me because there is a presupposition there that blind people are incapable of learning by example like it a sighted person learns – which is totally inaccurate. We can't, won't learn visually, but there are other methods through which demonstration happens. My father called me into the kitchen when he's cooking certain things, and tells me what he is doing. I can smell what he's doing; I can hear what he's doing. So the assumption that, once your sight is gone, environmental and incidental learning becomes impossible is nonsensical.<sup>206</sup>

**Math.** Knowledge and skills in mathematics was a subtheme that recurred with all participants, although they expressed varying levels of success and interest with the academic subject. Alex was majoring in theoretical mathematics at his university,<sup>207</sup> and Martin was enjoying a college Algebra course and looking forward to statistics and other university math classes.<sup>208</sup> Darik described having excellent math teachers

as well as serving as a math tutor for another student with visual impairment.<sup>209</sup>

However, all three female participants expressed frustration with mathematics. Janessa was perhaps the most conflicted, saying,

...I thought about it, and I was like maybe math, I like numbers... Once I got into Algebra Two, I was like “No, this is too much math. I don’t like this. Logarithms!” But once I got to college... a teacher pointed it out to me, she’s like, “You’re really good at math.” Like the easy problems, I would get mixed up on, but the hard problems I would get right. And it was strange how it worked. I was like, “This is hard! How am I stuck on the easy ones?” I never understood that. So I thought I wanted to go on to accounting and I really had it, and I was like, “Okay, this is going to be a major.” Then once I got into Excel, I was like “Oh no, no. This is getting ridiculous.”<sup>210</sup>

Brianne reported that she never learned to use the abacus (a common tool to aid students who are blind with mental arithmetic) and that she preferred a talking calculator, “because,” she said, “I hate math!”<sup>211</sup> Discussing her K-12 experiences, Tess – who said “I hate math but I’m somewhat of a numbers person”<sup>212</sup> – connected her struggles with mathematics to her visual impairment. She explained, “Math and science were hard for me. I think that a lot of blind people struggle. I mean there’s a lot of visual aspects to that.”<sup>213</sup>

Whether math knowledge connected participants to a passion and career or created a roadblock and source of anxiety, participants connected this subject with their experiences and/or future more than any other branch of academics. Furthermore, the ability to manage basic mathematical tasks connected to students’ budgeting and finances and to their overall success in formal education.

**Writing.** I was surprised to find a second academic skill area, writing, discussed in the transcripts of all the participants except for Tess. For Alex, who wanted to be an author and who was planning to write a travel blog while on his

adventures, writing skills were a key component of his future plans.<sup>214</sup> Similarly, Martin highly valued his instruction in writing and kept up an online blog about technology and blindness.<sup>215</sup> Darik was pursuing a career in journalism (although written journalism was his second preference, after radio)<sup>216</sup> and had recently scored well on the required grammar, spelling, and punctuation exam, despite having to work through significant accessibility issues.<sup>217</sup> Brianne confessed to a love of writing music but not other types of writing,<sup>218</sup> while Janessa experienced writing as a tedious and exhausting part of the coursework for her degree in hospitality. She said,

At first I thought English was going to be my favorite class, but turned out it was just too much paper to write... I was like, “I don’t like writing!” So I don’t know [laugh]; it’s like English is not my subject.<sup>219</sup>

**Career and college preparation.** The final knowledge and skills subtheme common to all participants involved awareness of important information about colleges and careers. Career education is one of the nine areas in the ECC; the American Foundation for the Blind explained, a “disadvantage facing the visually impaired learner is the lack of information about work and jobs that the sighted student acquires by observation” (2014, para. 9).

In the interviews, participants discussed ways in which knowledge of specific job skills and the college admissions and job applications processes was important to their decision making and pursuit of goals. Tess, like many other participants, was so involved with the academic curriculum in high school that she had little time for specific job, college, or career preparation instruction from her TVI and O&M Specialist. At the time of the interviews, she had been seeking job training from the state rehabilitation services department to assist her in gaining part-time employment,

and she expected to continue seeking that support even when she relocated to a new state for school.<sup>220</sup>

Darik's lack of knowledge and experience with the college admissions process likewise was a challenge to be overcome, one in which his parents (first generation immigrants, also new to the college system) could not assist him. He said,

I just came up here [to his university]; neither of my parents had attended college. And I did not have at that time any connection with people who had gone to college. So none of us knew the ins and outs of the process here in America. I mean, we didn't know that dormitories cost money, that books cost money, that the classes themselves cost money. We just thought, you know, you go to college. You got a scholarship, it's paying for everything. You know? Not knowing that dormitories could cost, what? At the least \$4,900 a semester. Plus the hidden dining charges to use the dining room. And we had no idea any of that.<sup>221</sup>

Brianne thought she might like to take college courses to become a social worker but realized she needed much more information about what the courses entailed, how to access visual resources and transportation, and even which school she could go to pursue training.<sup>222</sup>

**Other codes.** As happened with my development of some of the other major themes, I applied codes to segments relevant to knowledge and skills which did not directly relate to the above-mentioned subthemes and which were not universally discussed by all participants. Nevertheless, these themes help provide a more complete description of the major theme and the connection between this knowledge and skills and QOL. These additional codes included cultural awareness, legal knowledge, and social skills.

For Darik, cultural awareness began as early as preschool. He explained,

It's important for a kid to develop cultural – how should we say – there is cultural currency which we all share in common if we have the same

experiences. That cultural currency allows us to communicate with one another along each stage of life. So, when we are in pre-K, everyone is talking about Barney, firemen, Arthur, Wishbone, Crazy Bus, that kind of thing. By the time you get to first grade, you are talking about other things. If I was separate, if I had not gone to preschool, I would not share a lot this currency. And, lacking that currency, like in that common cultural framework, it would emphasize isolation that is already there because of the disability. So, it's just very important to go to pre-K for that reason – to develop that cultural framework.<sup>223</sup>

Alex's interest in cultural awareness was more international, and he explained that his desire to venture out and seek new experiences was linked to both his prior knowledge about other cultures as well as his desire to continue learning more.<sup>224</sup>

Brianne, Darik, and Tess all touched on the importance of knowing about the laws relevant to equal access for persons with disabilities. When traveling overseas, Tess even researched international dog guide laws, saying,

the guide dog laws [in France] are pretty much the same as they are here. I'm allowed to take her anywhere I go. Now, I did keep her records, her health certificate and stuff with me just to be safe. And I carried a copy of the guide dog laws in French and English.<sup>225</sup>

Likewise, Darik stayed abreast of dog guide laws and used his knowledge when necessary to self-advocate for his right to enter a public building with his dog guide.<sup>226</sup>

Brianne felt she would have had been able to defend herself better when her high school track team stopped allowing her to compete with a sighted guide if she had been aware of the relevant laws.<sup>227</sup>

Finally, participants shared their thoughts about the importance of social skills, which is also an ECC area (American Foundation for the Blind, 2014). Alex recognized that in fifth grade, he became more confident in his “ability to interact with people in a normal social way,”<sup>228</sup> leading to greater inclusion with his peers. Darik again credited his parents with giving him social skills particular to integrating with



sighted people, saying,

[R]ight now I'm looking towards you and the tape recorder. As opposed to looking down. At one point, [I was] like, "Well, it doesn't matter." But now I know. This wasn't something I had to go to a school to learn, but my parents taught me early on... They knew I turned my ear toward people because that's where my source of information was. Right? But, in the sighted world... I have to look at you with my eyes in order for you to perceive that I'm having a conversation you. And so my parents just taught me that as a general course, as a general part of looking confident. And so, now my ear is away from you; so I'm having to work a little bit harder to – it's less convenient for me to hear you I guess. But oh well. I'll ask you to repeat yourself more. That's your trade-off. You know?<sup>229</sup>

### **Internal Support System**

The last major theme from my interviews paralleled the previous theme, *external support system*, but instead involved the internal characteristics of participants which they relied upon in order to lead the lives they wanted to lead. This theme was separate from knowledge and skills in that it described dispositions or attitudes – more psychological than intellectual – and it could be distinguished from interdependence and independence because these dispositions did not necessarily involve any relationship to other people. However, as previously stated, all the major themes and subthemes are very much interrelated, and their connections are a good illustration of the complexity of QOL for the young adult participants (as conveyed in Figure 4.1).

I identified five subthemes for the external support system, with each subtheme representing an attitude or disposition which the participants connected with QOL. Two of the subthemes (*confidence* and *working hard*) were described by all six participants, and three (*contentment*, *adaptation*, and *proactivity*) were described by five of the six. Table 4.7 details the frequency of text-segments for each of these sub-

themes in each participant's transcripts. The within-participant variations in subthemes provide insights about the various personality or psychological characteristics which were most significant in each participant's experiences.

Table 4.7

*Frequency of Text Segments Connected with Internal Support System Subthemes for Each Participant*

Subtheme	Alex	Brianne	Darik	Martin	Janessa	Tess	Total
Confidence	<u>14</u>	1	<u>14</u>	4	5	10	<b>48</b>
Working hard	1	<u>3</u>	10	4	4	<u>19</u>	<b>41</b>
Contentment	3	0	3	3	<u>9</u>	10	<b>28</b>
Adaptability	4	0	3	<u>7</u>	1	7	<b>22</b>
Proactivity	1	2	11	1	0	2	<b>17</b>
Total text segments	23	6	41	19	19	48	<b>156</b>

*Note:* Underlining indicates the subtheme(s) most frequently reported for each participant.

**Confidence.** Together, the words confident and confidence occurred 25 times and were present in the transcripts for all participants except Brianne (in whose interviews the subtheme was still present, just not explicitly). Confidence was related to participants' ability to act independently (self-advocacy, self-determination, etc.) and interdependently (being social, accepting help, etc.) and enabled the young adults to take advantage of experiences and external supports and to both gain and apply knowledge and skills.

The positive aspects of confidence included self-awareness and self-acceptance. These were very powerful notions in Darik's life as he grew to understand and acknowledge himself not only as blind but also as deafblind. He said, "Before I figured out I was deaf blind, I thought I was the only blind person who had combined hearing and vision loss;"<sup>230</sup> however, since accepting and becoming confident in

himself and his strengths and limitations, he has become more assertive and articulate when pursuing assistance or independence.

Self-confidence also benefitted participants in responding to insensitivity or misconceptions. In my field journal on April 29, 2014, I described a tension between being pitied by others and being seen as having super powers which made it difficult for participants to know just how to react to strangers. When discussing responding to attitudes of pity from others, Martin said,

I think that it's just a matter of presenting yourself as confident. You know, making the choice to advocate... speak loudly and be really proud of who you are. I mean that whole thing, and you know maybe the sighted individuals around that person will have more respect. You know, they'll be a bit more understanding of their situation, and then the blind person is able to interact with them without any problems.<sup>231</sup>

On the flip-side, there were times when fear and self-doubt prevented participants from being as confident as they would have like to have been. Tess said,

To some degree, in the back of your mind, if you are making a friend, and you're just getting to know them, you're afraid – because you're afraid if you tell them the wrong things they'll think that you are needy, and then they'll want to be – I've had people do this, okay. They'll want to be your friend because they feel sorry for you, not because of who you are. And I've had people do that to me. They've been my friend because they felt sorry for me, and not because of who I was as a person.<sup>232</sup>

During middle school, Janessa said she was "... afraid to talk to people. I didn't want to admit that I was lost or that I needed help,"<sup>233</sup> and Darik lamented, "I had some opportunities in my life that I missed because of fear, uncertainty."<sup>234</sup>

**Working hard.** The second subtheme of internal support system that was common to all participants involved the necessity of a strong work ethic or willingness to put forth extra effort. For Brianne, this meant overcoming the difficulties imposed by her short and long-term memory challenges and working especially hard over long

periods of time to master important travel routes.<sup>235</sup> Janessa credited her parents as role models for her of what it means to work hard. She said

My mom and dad are both hard workers, I think that's where I get it from. Because although I might have fun, I also know what I need to get done, and know how to balance, the work-life and the fun, socializing. And that's how my mom is. Although she works, eight hours a day, maybe sometimes it's even seven days a week, she still knows how to balance out her social life.<sup>236</sup>

Working hard also included experiences when participants took on additional responsibilities. Tess advocated that, in determining if a high school student could get a dog guide, TVI's, COMS, parents, and dog guide schools should be less worried about the high school environment and should consider how responsible the student would be. She explained,

There's as much responsibility in a car as there is than a guide dog. Yes, it's different. Yes a guide dog is alive. And it's a different type of responsibility. You are responsible for another being. But I would argue that the responsibility for handling a guide dog is as great as the responsibility of handling a car. And if a sighted 16-year-old is responsible enough to be given a car, then I darn well think that a 16-year-old blind student should be allowed to get a guide dog if they are responsible enough.<sup>237</sup>

Likewise, when asked about the added work that came with having a guide dog, Darik responded that he happily accepted the responsibilities that came along with his dog.<sup>238</sup>

The antithesis of working hard is "giving up" or "giving in" too easily or quickly when things become difficult. Alex expressed, "[A] lot of blind people might be disillusioned with the working climate, as it can be difficult for a blind person to get a job. It is difficult. So I can see that, I can see people giving up."<sup>239</sup> When life gets hard, Tess explained, "Well it just means, well it sucks. And it's painful. But, what can you do? You can't give up."<sup>240</sup> Working hard allowed participants to continue to

make progress towards their goals, even when other support systems failed or access issues were stacked against them.

**Contentment.** All of the participants except for Brianne talked about the relevance of being content – to varying extents – with the way things were and with things that were beyond of their control. For Tess, contentment was a way to self-evaluate her QOL; she shared, “Quality of life means am I... content? Not even necessarily happy. But am I content?”<sup>241</sup> Likewise, Alex said, “When things are going well I’m very content... as opposed to restless. When things are... not going as I want them to, when my life isn’t going the right direction I feel very discontent, and very restless.”<sup>242</sup>

One aspect of contentment for participants was optimism and staying positive about present circumstances and possibilities for the future. For Janessa, “staying positive” was essential for helping things to go well. She said,

Don’t think negative thoughts. Because once, I would say, “Oh, I might not get this.” Next thing you know, I don’t get it. Well, I was like, well, I already expected that. But if you look at it like... this will happen. And you look, and you see it. It just will come to you in the future.<sup>243</sup>

Martin and Tess also specifically credited a positive attitude for helping things to go well in their lives.<sup>244</sup>

Participants further indicated optimism and the subtheme of contentment when they reflected on the role that luck has played in their lives, giving credit to happy circumstances that happened without a need for their intervention. Janessa used the words *luck* and *lucky* five separate times in reflecting on instances when she was pleased with the way her life turned out, from her ability to attend a community college with a dorm to her good fortune with the transportation system around her

transition program.<sup>245</sup> Martin also credited some important circumstances in his life to good fortune, saying “I’ve been lucky enough to gain a lot of knowledge about... how to navigate the websites.”<sup>246</sup> Half-joking about the future and having a family, he said, “I mean I guess if I get lucky, I get lucky.”<sup>247</sup> Recognizing that parts of their lives were beyond human control – thus, up to luck and chance – was a sign that participants valued contentment and acceptance of at least some aspects of their lives.

**Adaptability.** All participants except Brianne also discussed the importance of the disposition of adaptability to the quality of their lives. Alex described his willingness to adapt to a new situation when he explained a down-hill skiing adventure:

Well, the thing is the way they used to do it, I think the way they still do it, is that they put tethers on the blind person’s ankles and have a sighted person ski behind them... To me, that just felt like I might as well sit on a sled. It didn’t seem like I have any control it all... So I had them, instead, give a list of numbers, 1 through 10 – 1 being the extreme left, 10 being the extreme right – and call out every two seconds where I was on the path; so, that way I could make my own decisions... And for the most part it worked; it actually worked very well. And it gave me a much greater sense of freedom and it was very fun. The only times it went badly was when they mixed up their numbers – called, “10, 10!” and I desperately go the wrong direction and smash into a tree or something like that. But it was fun, it was definitely worth it.<sup>248</sup>

By being a bit creative and flexible, he was able to participate in a way which allowed him more independence and gave him greater personal satisfaction.

Adaptability also means learning from prior experiences in order to improve circumstances in the future. Tess declared, “What you learn in your life, whether it be something that someone else taught you or something that you learn by going through an experience by yourself, sure that will help you moving forward.”<sup>249</sup> For Janessa, “being able to say that you went through something, but at the end it was better. It got

better” was key to improving QOL.<sup>250</sup>

**Proactivity.** This final subtheme under the major theme of internal support system was discussed by all participants except for Janessa. Proactivity involved participants’ initiative to seize opportunities and be assertive, rather than passively accepting the status quo. Darik shared,

[N]othing hurts like a missed opportunity. Nothing. I had some opportunities in my life that I missed because of fear, uncertainty. And as successful as I think myself to have become, those missed opportunities haunt me. It’s one of the curses of having a good memory, you know very, very well what you screwed up on. And, so, don’t miss opportunities.<sup>251</sup>

For Tess, being proactive and assertive came naturally but was especially helpful in learning to work with her dog guide. She said,

It’s just part of your nature to be assertive. I mean, in guide dog class they did certain scenarios where a trainer would pose as an interested pedestrian coming up and wanting to say hi and distract your dog, or whatever, and they teach you how to handle that. ...You have to have a certain assertiveness about you to handle a guide dog because at the end of the day, they are still a dog. They’re still going to test you; they’re still going to push you. Having a disability, in order to be successful you need to be a little assertive anyway. Obviously I might be a lot more assertive than some people, but [laugh] you know. You know.<sup>252</sup>

Participants also described times when they were passive, not proactive – especially Brianne. With regards to finding a trusting friend, she said, “I pretty much have to wait for them to come into my life,”<sup>253</sup> and her reaction to not knowing a particular social skill was, “Well I’m just pretty much thinking that I didn’t know; I was never taught. So there’s not really much I can do unless you teach me.”<sup>254</sup>

Through these shared experiences and insights, participants described how being proactive (or being passive) could be an important factor in their experiences and independence, further demonstrating the interconnectedness of these six major



QOL themes.

### **Additional Findings: K-12 Experiences**

After analyzing the data for themes, I reviewed the transcripts for additional participant stories and experiences related to my first, secondary research question, “How is the essence of quality of life as experienced by young adult students who are blind influenced by the student’s primary and secondary school experiences?”

The theme *knowledge and skills* and the subtheme of *education and learning* (within the theme *external supports*), combined with additional specific experiences from participants, provided insights about the influence of primary and secondary school experiences on participants’ QOL.

The six participants in this study all attended local, public schools for all or the majority of their K-12 educational experiences. However, Martin did describe his high school years at the state school for the blind as a positive fit for his needs. He said,

[I]t’s really interesting because some people think well... that... schools for the blind in general are like really, they’re really accessible to the point where it’s not real and the real world. But, I honestly think that, you know, the schools for the blind, they are really accessible and that’s how they’re designed to be. That’s how they’re supposed to be. But if they go to the school for the blind I believe that, if they get the proper training, then they can eventually go out there in the community and be able to participate in many of the things out there in the community.<sup>255</sup>

Martin particularly appreciated living and attending school with other students who were blind, who he described, saying

I never really knew, but there was so much talent when I got here. There was like all these students possessing all these different talents and, so many people can sing really well. Some people can utilize technology very well; you know I just learned some of the skills while I was here.<sup>256</sup>

When talking about his experiences at the school for the blind’s summer

programs, Alex said,

I came to a few technology camps. I think I came to music camp as well, but they were more social activities for me than anything else. At that point I still had more friends among the blind community than I do now. So at that point it was more coming to socialize at as it was to learn anything.<sup>257</sup>

Janessa credited one particular summer program, which included work experience in the school for the blind's snack bar, for helping her overcome her shyness. She said,

[W]hen I first went to the... program, that was my summer job. And there I talked to everyone, and I was like "Okay, I don't have to be shy anymore." So, I talked to a lot of people. And that rolled into college, so that's how I got a chance to be with my, talk to my roommates about, like, "Okay. Yes, I'm blind, but I'm no different from anybody else." And that's how they started warming up to me, and I was like, "Okay, being shy is not – it don't get you anywhere." So once I came to [rehabilitation center], I was all, I don't know, I guess social, talking to people, and that's how I started making friends. Hanging out with them.<sup>258</sup>

Two participants (Alex and Darik) described participating in International Baccalaureate (IB) programs in their public high schools, which is a specially accredited classification of high school programs with very high standards for students and teachers. Janessa, Tess, and Martin also mentioned taking advanced or honors level courses. Alex and Darik were highly appreciative of their IB education, and all participants described the benefits of having good teachers and challenging courses.

All participants also had positive feedback about being included with sighted peers during their K-12 instruction. Darik shared,

So, nowadays I see where they have whole class periods where blind people are separated from the mainstream. Like, I was volunteering with two blind middle schoolers, and they probably take three days out of the week where they'd have a whole block devoted to an itinerant vision teacher, I didn't have that, and I'm frankly glad I didn't have that. I had about, at most, 30 minutes – for O&M, maybe an hour, but very short periods of time with the itinerant vision teacher to go over crucial stuff like braille, etc. And again, all the way

through fifth grade, I was otherwise left alone. Which is fine! Absolutely fine. Went on the playground with the kids, you know? No special, no special segregation whatsoever. Middle school, essentially the same thing.<sup>259</sup>

Brianne viewed some of the weaknesses in her educational program as partially responsible for her later challenges in pursuing her goals. She explained, “...my TVI didn't teach me much; she just was there to make sure I was doing work and I had the work... to where it would get done, or she would be there to help me, to be my scribe, sometimes.”<sup>260</sup> Her most positive recollections of high school had little to do with being included, rather they related to the support she received from a diagnostician and a TVI when she struggled to obtain physical, financial, and legal independence from her mother.<sup>261</sup>

Tess vividly described how another aspect of inclusive public schools – her peers –affected her school experience and continued to impact her post-school decisions and dispositions. She explained,

[F]rom about sixth grade ‘till like my junior year in high school, I got bullied every day. And by bullied, I’m talking people called me an “f-ing” female dog... People told me I didn’t deserve to live. I would get hit, kicked, tripped, and people would laugh and watch me fall. And the teachers and school administrators did nothing, claimed that they could do nothing about it. It got to the point where I didn’t feel safe eating my lunch in the cafeteria because people would play with my food. So that was definitely tough. I mean, what, six years straight? Pretty much every day. That was hard. I mean that’s going to be tough no matter who you are! Or what kind of family support you have at home. That’s going to be tough right there.<sup>262</sup>

In high school, Tess finally found a social group that accepted and included her, first with students in the ROTC program and then with peers from her science class. She explained,

So, like once I got a group of friends kind of going, people left me alone. The bullying didn’t totally stop, but it was a lot better. I’ll put it this way, the end of my junior year, and really my senior year. I finally could walk down the hall

without having to keep my head up and keep looking over my shoulder, wondering if anybody was going to throw anything at me.<sup>263</sup>

When I asked if she thought things would have been easier had she attended a school for the blind, given all of the abuse she had suffered at the hands of sighted peers, she conveyed that the benefits of being with her external support system (her family and the group of friends she ultimately connected with) outweighed any benefits of going to a residential program. Tess said,

... [I]f I could go back and change it to go to the school for the blind, I don't think I would. But, like for example, take interacting with sighted peers. Okay. So I say that it's better to try to live in as normal of a world as you can have, I mean it's nice to have both sighted and blind peers. But to live in a primarily sighted world. I thought was better, and probably I still think would be better for me at that age. You know, 10, 15, whatever. However, in somebody else's situation, they might not have had the opportunities that I had growing up, with a supportive family and a church and stuff. And they might – for them, being able to be in a primarily blind-person-world, you know, where there's mostly blind people like them, or whatever, might be better for them. But it's hard to say... I think it just depends on the person and their life, and their circumstances around them.<sup>264</sup>

In Chapter 5, I discuss the relevance and impact of these diverse K-12 experiences.

### **Summary**

This chapter provided a detailed account of the six major themes that I identified during my analysis of the transcribed interviews. To support the trustworthiness of these findings, I also provided personal reflections on the extent to which the themes and subthemes resonated with my experience as a TVI, and existing emphases in the field of special education for students with visual impairments, including the ECC. Tables 4.1 – 4.7 provide additional evidence of the extent to which these themes were emphasized across all participants and within the transcripts for individual participants.

The following chapter discusses these findings in light of the research questions for this study and includes possible implications of this six-theme perspective for future research and for current practices in special education and programs and services for young adults with visual impairments.

## **CHAPTER V**

### **CONCLUSIONS**

In the previous chapter, I describe a six-theme model for understanding quality of life (QOL) as experienced by young adults who are blind, based upon the analysis of my transcribed interviews. The six participants in these interviews could not speak for all young adults who are blind and certainly could not speak for all people with visual impairments; however, their shared experiences provided a foundation from which we can continue seeking a better understanding of QOL. In this final chapter, I return to the original research questions for this study and discuss what can be learned about each question based upon the findings of my research. While responding to these questions, I also share other insights beyond what was originally sought through the research questions. Finally, I discuss the implications of the answers to these questions, and I offer recommendations for those who are currently working in the fields of special education, disability services, and visual impairments. I end with a discussion of next steps for additional QOL research with people who are blind and visually impaired.

#### **Answering Research Questions**

The following sections answer the three research questions posed in previous chapters by reflecting upon the findings from the transcript analyses.

##### **Primary Question**

Quality of life for young adults who are blind can be described using six major themes: external support system, experiences, interdependence, independence, internal

support system, and knowledge and skills.

In the voices of my participants, I found stories that would likely resonate with many young people, with and without disabilities, as well as unique experiences, abilities, and needs which pertained to being blind in the cities and towns of the southwestern United States. In Chapter 4, I discussed the six themes and their subthemes in detail, using direct quotations from the participants. The following paragraphs convey my personal reflections on each theme and its relevance to QOL.

**External support system.** The participants in this study were at various stages in their personal transitions from childhood to adulthood and from school to employment. As with most young people, they were leaving a world of structured, somewhat artificial supports (such as the Individualized Educational Plan guaranteed to students with disabilities in K-12 schools) and entering a world where they would have to arrange and advocate for the supports they choose to use. Thus, the components of an external system of supports were top-of-mind and frequently discussed during the QOL interviews.

As Americans over the age of eighteen who had become their own legal guardians, the six participants had an array of options for organizing the new support systems that would assist them through future phases of their lives. However, they were both influenced and limited by the presence and absence of supports in their pasts. Brianne struggled to imagine herself not relying on government assistance, having been raised in an environment which did not treat her as capable. She grew to believe that she had little other recourse but to pursue most any source of income which would cover her rent, while Tess's parents modeled self-reliance and high

expectations, prompting and enabling her to pursue a career that fit with her passion and interests.

Parents and families were an important component of the external support system throughout participants' lives. The young adults reflected positively on times when they were treated similarly to their sighted siblings and felt restricted by instances of parental overprotection or micromanagement. Even when participants disagreed with their families, they generally valued having parents and older siblings to talk with, to confide in, and to ask for advice. While five participants' stories demonstrated the positive influence of parental support on QOL, Brienne's experiences provided further evidence that the absence of parental support could be detrimental to QOL.

The role of rural communities also stood out in this theme of external supports. Blindness and visual impairment does not limit itself to large urban centers, though that is where sighted people often encounter the "successful" people with blindness and visual impairments. Perhaps this is because urban centers inherently contain many valued external supports – transportation, education, offices for state and social programs – thus attracting those who do not already live in urban areas to relocate. A self-supporting blind community can develop and even recruit others when a sufficient number of people relocate to an area, although online networking is increasingly creating a virtual blind community that can be accessed from anywhere. For these reasons, young adults in rural areas face tough decisions as they become aware of the greater supports offered in larger cities – whether to stay within the system of family and community supports that they have always known, or follow the path of many of



their peers with visual impairments, leaving families behind for greater opportunities and connections with others who are blind and visually impaired.

Finally, as I anticipated, technology was also a major component of students' external support system. Young adults who are blind must learn to use assistive technology (AT) like screen-reading software, braille displays and note-takers, i-devices, etc., although my participants expressed a variety of ways to become proficient. Martin reported to have taught himself – using web-based resources – most of what he has learned about computers and technology, while Darik was most pleased with the instruction he received from other AT users who were blind. Alex also felt that there were limits to what his sighted TVIs could teach him about AT. For all participants, AT as well as popular consumer technologies were essential to their social and career aspirations and planning for the costs and acquisition of these tools was an essential to achieving their goals.

**Experiences.** One of the chief objectives of the modern international disability rights movement is the closing of institutions where people with disabilities have historically been housed from birth to death as a “public service.” I could argue that these orphanages or state homes do provide an external system of supports – perhaps even loving parent figures and education; yet, the most terrifying aspect of institutions is that they deny people access to experiences.

Experiences allow us to grow, learn, change, and become who we want to be, and the six participants in my study all strongly desired to be able to experience the world around them. Blindness, along with its associated challenges of inaccessibility and limited transportation, can easily lead to lives of limited experience. In fact, TVI's

are trained to understand the impact of limited incidental learning (children not learning because they are not naturally exposed to what is going on in their environment) (Wolffe, 2000). This limited interaction with learning opportunities is not just a result of children's inability to see what is going on. Children who are blind need to go places, to meet people, to try new skills and to have adventures just like their sighted peers, and parents and teachers must be innovative and not overly protective to make sure that these experiences take place (Koenig & Holbrook, 2000; Wolffe, 2000).

As young adults, my participants were self-aware about their desire to experience the world. Their realizations were borne out of encounters with boredom, tastes of adventure, and a desire to be included in the world around them. Education and rehabilitation programs provided these students with a greater awareness of opportunities and options, further fueling their confidence and desire to engage with their surroundings. Thus, each new experience set in motion more experiences and opportunities for enriching one's life, providing occasions for purposeful and meaningful contributions as well as personal outlets for anxiety and stress.

In my researcher's journal for April 27<sup>th</sup>, after reviewing Brianne and Janessa's transcripts, I described the sense of a continuum in participants' experience, with boredom at one end and adventure at the other. The particular place on that continuum which is most ideal for each participant varied – Martin, for example, did not seem to seek the same level of adventure as Alex, but to some extent, the idea of being “in motion,” or at the least “not bored” was prevalent throughout the interviews.

**Interdependence.** The theme of interdependence reminded me that QOL

rarely comes from what you have; rather it is fundamentally connected to the other people with whom you share your life. Human civilization has developed with intrinsically visual properties. For all of human existence, the majority of people have been able to use vision for navigation, religion, communication, education, commerce, etc. Those sighted people built roads, churches, writing systems, schools, and businesses which are designed for visual access. For someone who is unable to access the world visually, this civilization could become a prison – as described in the Nobel Prize-winning novel *Blindness* by José Saramago (1995/1998). Perhaps this is why so many people express a fear of blindness (Giridhar, Dandona, Prasad, Kovai, & Dandona, 2002) and/or show astonishment when they learn of the successes of a person who is blind in a sighted environment. What often goes unstated is the important role played by interdependence, especially for someone who is blind who wishes to escape the captivity of limited accessibility and take part in the “sighted world.”

The dominant American culture upholds our Declaration of Independence not only as a founding document, but also as a value statement. Whereas other societies and cultures place a higher value on interdependence, most American children are raised to strive for self-reliance and self-determination. In my study, participants discussed the challenges and importance of interdependence in every aspect of their lives. From the first connection with an early childhood service provider to asking a friend for a ride to the pub, they needed to collaborate and cooperate if they hoped to succeed. As teenagers and young adults, the desire and pressure to be independent and this need for interdependence can be unsettling, leading to some trial and error, not to

mention tensions within the external support system!

Each person – with or without blindness – has to find a personal comfort level with being interdependent with others. Likewise, each new encounter with a fellow human being is a new testing ground for being accepted and supported or rejected and restricted. For people with visual impairments, these interactions are influenced by their own comfort as well as the importance of access, the limited availability of alternatives, and the willingness of others to cooperate.

Exclusion, whether overt and intentional, or simply perceived by someone who is blind, can have negative emotional and social consequences as with Martin's experience of continued omission of accessibility on the part of game designers and other computer programmers. While perhaps not intentional, this resonated as insensitivity and social exclusion to a young man who has invested so much energy and time into becoming a part of the online gaming community and the computer programming field.

**Independence.** While interdependence is crucial for young adults who are blind, they must also find adventures, responsibilities, and decisions to undertake on their own. At the age of 18, the participants in my study found themselves both blessed and burdened with the legal freedom to make decisions for themselves. Some had extensive prior experience with independent travel and/or had taken initiative at school or with organizational projects; others were less sure about operating on their own. As discussed with the theme of interdependence, social and family pressures for and against independent behavior also played an important role.

For someone who is blind, independence also involves freedom to plan and

schedule life's experiences without having to compare schedules or seek permission from anyone else. Access to independent modes of transportation provides an incredible boost to independence because people are enabled to come and go as they please. Of course, different forms of public transportation have various costs and provide varying levels of access and flexibility, evidence that independence will always be limited by the external support system.

**Knowledge and skills.** As a professional educator and specifically as a TVI, my career has been shaped by the necessity of imparting knowledge and skills which, I hope, will enhance the QOL of my students. However, this research project provided the opportunity to hear from experienced students about the particular types of information and techniques which they found most relevant.

Orientation and mobility and braille were certainly essential to my participants' QOL, although I admit that my sampling strategy made it unlikely that I would meet students who did not have at least basic skills in these areas. I could clearly see how being able to navigate routes and use public transportation was just as important as having access to a bus or train system. Likewise, braille provided the foundational skills for accessing the general education curriculum, even for students who later preferred auditory materials.

In my field journal on April 24, 2014, after meeting with Alex, I reflected on my experience as a TVI, having met other students who were blind as a result of retinoblastoma. Alex – and the two other participants with the same eye condition – reminded me of previous students in my time as a TVI. I noted that there are common “knowledge and skills” often associated with retinoblastoma by TVIs – especially

excellent orientation and mobility skills and strong academic abilities – and I wondered to what extent this stereotype might lead to a self-fulfilling prophecy?

Could it be that professionals anticipate that students with visual impairment resulting retinoblastoma will have greater skills and therefore have higher expectations?

National advocacy groups discussing education for students with visual impairments have placed major emphasis on the Expanded Core Curriculum (ECC), especially social skills and independent living skills. The American Foundation for the Blind advised, “The skills and knowledge that sighted students acquire by casually and incidentally observing and interacting with their environment are often difficult, if not impossible, for blind and visually impaired students to learn without direct, sequential instruction by knowledgeable persons” (2014, para. 7). However, most of the participants in this study share experiences of being successful without significant or direct professional intervention in independent living and social skills. Martin received this instruction by virtue of his high school experience at a school for the blind and visually impaired, but he emphasized O&M instruction and described learning many daily living skills on his own or with his peers. Alex, Tess, and Darik explained that there was not enough time during the school day – given their fully included academic schedules – for daily living skills. They primarily relied on their parents for this training, with additional support from short-term, summer or post-secondary training. Only Brianne, who described having little to no opportunities to learn from her parents, wished her K-12 experience had included more social or daily living skills instruction. Notably, Brianne also had cognitive/processing challenges that none of the other students exhibited, which may have resulted in her need for more direct

instruction in many skills.

As a TVI, the participants' experiences caused me to question the extent to which we emphasize direct instruction in social and daily living skills, particularly for students who are succeeding academically and who have supportive families. A recent study on social competence by Botsford (2014) – who interviewed employed adults who were blind – also suggests that social skills are more influenced by parents and families than by direct instruction from teachers. However, I also believe that my participants represent an exceptionally independent sample of students who are blind – their circumstances do not resemble the lives of most of the students with visual impairments I have known during my teaching career.

I was somewhat surprised to hear participants discuss writing skills as important to their QOL; however, written communication plays an important role in exchanging information and accessing resources. Blogs and social media platforms mean that interacting with others could easily involve headphones, fingertips, and keyboards, rather than phone calls, lecture halls, and coffee shops.

Taken as a whole, the theme of knowledge and skills is evidence of the great potential for formal and informal education systems to influence QOL for persons with visual impairments. Some learning will be done in the classroom while other information will be acquired through experience or through reaching out to the blind community. The challenge for teachers of students with visual impairments is to identify and respect the continuum of abilities and skills that students possess and seek to possess, and to help in shaping truly individualized, life-long learning.

**Internal support system.** Of all the six themes in the model of QOL which

emerged through this study, the internal support system seemed the most difficult to access directly. As a TVI, I have ideas about helping students become independent and interdependent; I know what it takes to help students access experiences, supports, knowledge, and skills. However, developing an internal support system – confidence, work ethic, adaptability, etc. – is the process of a lifetime and a myriad of influences.

Furthermore, there is no one best combination of internal supports. For some people, contentment is more important than proactivity in determining QOL, while others are not happy unless they are seizing opportunities and testing the limits of their abilities. Likewise, internal supports such as confidence and contentment can be components of a toolbox for achieving other goals, or they can become the ultimate outcomes by which people measure their QOL.

**Interconnection of themes.** Throughout Chapter 4, as I explored each theme, I discussed the interconnections amongst the themes and subthemes in this emerging model of QOL. It would be impossible to select an experience or story from any participant's life that did not involve multiple themes, and no one theme can be said to influence QOL without also connecting to other themes.

I believe that this multi-element model, comprised of internal and external elements, dispositions, skills, and experiences, emphasizes the complexity of life as it is experienced by my participants.

### **Secondary Question 1**

The essence of quality of life as experienced by young adult students who are blind is influenced in multiple ways by the student's primary and secondary school experiences. The stories shared by participants revealed that K-12 school



environments have numerous impacts on QOL for students who are blind, both while students are attending and after they graduate.

While the importance of residential schools for the blind was neither supported nor negated by participants, they did see social benefits to taking courses alongside other students who were blind, particularly in short-term and summer program settings. Schools for the blind and other settings specifically for blind people also provided participants with opportunities to develop particular talents and to learn from mentors and peers who were also blind.

Attending classes with sighted peers was also very important to all participants in this study, evidence of the fact that almost all students who are blind will ultimately need to be able to function in families and workplaces which consist, primarily, of sighted people. TVIs and other special educational professionals are crucial in facilitating meaningful inclusion – ensuring equal access to materials, providing instruction in braille and O&M, etc.; however students must also have quality general education teachers who are creative and flexible and who hold students to high standards, regardless of students' circumstances or differences. Additionally, school professionals must be diligent observers and facilitators of the social inclusion of all students, ensuring that young people develop and promote attitudes of tolerance and acceptance. Bullying and intolerance should be addressed immediately so that all students can feel safe within school buildings.

Further QOL research can provide additional insights into strong and weak elements of K-12 programs for students with visual impairments. Qualitative and quantitative data will help us to understand students' experiences over time and to

identify the particular types of supports and interventions which are most meaningful for students' personal development and future goals. To continue to understand and evaluate K-12 education and supplementary educational programs for students with visual impairments, we must consider – and have the tools to evaluate – QOL not only as an outcome of education but as an indicator of life satisfaction while students are still in primary and secondary schools.

## **Secondary Question 2**

The essence of quality of life experienced by young adult students who are blind has both similarities to and differences from the theoretical models, constructs, and indicators of quality of life present in existing quality of life instruments and research.

In particular, I will discuss how my findings compare to the QOL models of the IASSID SIRQ-QOL and the WHOQOL, described in greater detail in Chapter 2. These existing models are based upon quantitative research, and I do not have sufficient participants or data to do a thorough comparison of my six themes and subthemes with all of their domains and indicators; however I can describe certain similarities and distinctions.

**IASSID SIRQ-QOL.** The IASSID SIRQ-QOL proposed an eight-domain model of QOL, with multiple indicators for each domain (Schalock & Verdugo, 2002; Verdugo et al., 2012). Their eight domains are: *social inclusion, physical well-being, inter-personal relations, material well-being, emotional well-being, self-determination, personal development, and rights*.

IASSID's domain *self-determination* is a subtheme of my major theme,

*independence*. Likewise, the domain *material well-being* is directly related to the subtheme of *money* under my major theme, *external system of supports* and *personal development* relates to the major theme of *knowledge and skills* and the subtheme of *education*, under *external system of supports*. *Social inclusion* and *interpersonal relations* – two IASSID domains – have overlapping properties with my theme of *interdependence*, and there are also similarities between IASSID's *emotional well-being* domain and two of my themes: *independence* and *internal system of supports*.

Beyond these similarities, the organization of IASSID's domains and indicators and the structure of my themes and subthemes are quite different. IASSID emphasizes elements of the micro-, meso-, and macrosystems across all of its domains, whereas I have two separate themes: *internal support system* (comparable to the microsystem) and *external support system* (comparable to the meso- and macrosystems).

IASSID also offers two domains which I do not feel have counterparts in my themes or subthemes: *rights* and *physical well-being*. In listing exemplary indicators of the *rights* domain, Schalock and Verdugo (2002) included *privacy*, *self-determination*, and *self-advocacy*, which were addressed in my research; yet, while participants in my study discussed knowing their rights, the presence or absence of rights did not arise as a major theme or subtheme. If I had conducted this study in a different country or at a different point in history, I can imagine that the notion of rights might have emerged more explicitly; however rights do not seem a major concern at the present for the young Americans in my study. Interestingly, the domain *physical well-being* was also not apparent in my analysis of the interviews, perhaps

due to participants' apparent good health and their youth.

After comparing my findings with IASSID's eight-domains, my impression is that my six theme model of QOL for young adults who are blind is compatible with the IASSID model. The themes and subthemes I have identified could be reorganized to emphasize the micro-, meso-, and macrosystems, and evidence for all domains could be strengthened with additional research with people who are blind and visually impaired of varying ages and in diverse parts of the world.

**WHOQOL.** The WHO's Division of Mental Health and Prevention of Substance Abuse researched and produced a QOL instrument, the WHOQOL, to study health-related QOL around the world. Their longer version of the WHOQOL (WHOQOL-100) has a six domain structure (*physical health, psychological, level of independence, social relationships, and environment*), and the shorter version (the WHOQOL-BREF) was reduced to four domains (*physical, psychological, social relationships, and environment*) (World Health Organization Division of Mental Health and Prevention of Substance Abuse, 1997). Within each domain, the WHOQOL addresses multiple facets; for example, within physical health, the instrument considers *energy and fatigue, pain and discomfort, and sleep and rest*.

There are several similarities between the six WHOQOL domains and my six themes. *Independence* (my theme) is comparable to the domain *level of independence* in the WHOQOL. My theme of *external system of supports* and its subthemes are very similar to the *environment* domain and its facets. Also, my theme *internal system of supports* relates to the WHOQOL domain *psychological*. My domain *interdependence* straddles the WHOQOL domains of social relationships and psychological.

In contrast, my themes of *knowledge and skills* and *experiences* are not clearly present the WHOQOL domains, although the domain *environment* does include the facet “opportunities for acquiring new information.” Additionally, the WHOQOL domains *physical health* and *spirituality/religion/personal beliefs* do not have counterparts in the themes or subthemes from my study. The physical health emphasis – also noted in the IASSID model – was simply not discussed by my young, healthy participants with respect to their QOL, and spirituality was not discussed consistently across all participants. However, I believe that during additional studies with diverse groups of people with visual impairments, these themes would also likely arise.

### **Implications**

Presently, major QOL instruments like the QOL.Q and WHO-QOL are being used in pan-disability studies without any evidence of their validity or reliability for people who are blind or visually impaired. People with visual impairments are either excluded from these studies or included without knowledge of the appropriateness of the survey instruments. The intent of this research has been to develop a theoretical basis for a new or revised instrument that can be used in quantitative studies of QOL in populations that include persons with visual impairment.

My findings do propose a model of QOL for young adults who are blind, thus providing a basis for a mixed-methods line of research, including future quantitative instrument development and dissemination, to assist the international efforts to develop evidence-based interventions for improving the lives of persons with disabilities.

Additionally, I am honored to have included the voices of people with

disabilities in my research. Through a careful study of what six young adults have to share about QOL, I have been able to contribute evidence to enhance the practices and research in the fields of education and services for people who are blind. By reflecting on the six QOL themes of this study, we can consider the extent to which new and existing programs and services:

- help people acquire desired knowledge and skills
- bolster individuals' internal support systems
- promote healthy interdependence
- enhance independence
- offer access to desired experiences
- and improve access to and delivery of necessary and preferred external supports.

The experiences and voices of the six participants in this study should be of great value in the fields of education and special education (including school districts and teacher preparation programs) and in diverse public and social arenas. Community planners and transportation authorities can be better prepared to support people with visual impairments if they recognize the importance of their roles in the external support system. Likewise, advocates and political leaders can apply the themes and subthemes from this study as they develop and reform legislation on education and civil rights.

### **Recommendations**

The young adults in my study shared many anecdotes and powerful stories about experiences, people, and supports which have impacted their lives. My hope is

that we will continue to learn from and share these stories and stories like them because they paint a fuller picture of the opportunities available (and denied) to young adults with visual impairments in the United States. Clearly, these students are capable of accomplishing amazing things, and they are passionate about being full participants in society. We must continue asking questions and learning from their experiences as often as possible in order to address barriers and increase access to lives of quality and equality.

In order to develop a more robust theory of QOL for persons with visual impairments, the line of research that I began with this study must be continued in future studies. Additional qualitative research is needed with younger and older people, with K-12 students and with non-students, and with people who are blind as well as people with other levels of visual impairments. People with and without additional disabilities should always be included. This research should be conducted in the United States and overseas to ensure participation from various cultural and linguistic groups.

Through multiple studies, we can either provide evidence for a new model of QOL or consider the use of one or more existing models for studying QOL in populations that include persons with visual impairments. These new, revised, or existing models can then be tested with larger samples of people using quantitative methods, ultimately leading to measures of reliability and validity that will finally enable appropriate understanding and investigation of factors which influence QOL for people who are blind or visually impaired.

With validated QOL instruments, we can consider QOL as an important

outcome measure in human-rights efforts, educational programs, and beyond, and – in so doing – we will know that the work being done and the outcomes being measured are meaningful and relevant to people with visual impairments. This is my vision of “nothing about us without us” put into action, with the voices and stories of people with disabilities leading directly to the positive changes they wish to see for themselves and the future.

Furthermore, there are immediate applications for the themes and experiences developed and discussed in this study. More research needs to be done to determine the impact of daily living skills and social skills instruction for students with multiple disabilities including blindness and for students with less supportive families. We should consider to what extent TVIs and COMS can support families in teaching daily living skills and social skills at home to children who are blind or visually impaired – as parents typically do for sighted students. Additionally, we must continue to look for ways to use short-term, summer, and post-secondary programs to provide targeted supports for particular social and daily living skills that students are not learning at home.

School systems and educators must not be complacent or ignorant about issues of exclusion and intolerance faced by students who are blind. Bullying and social exclusion can have devastating consequences for students’ future independence and interdependence, and wherever these problems exist, schools should implement awareness campaigns, more accessible environments, and individual supports for students with visual impairments. At the same time, K-12 schools, colleges, and universities must also critically examine their academic and extra-curricular programs



to ensure equal access and non-discrimination so that students are able to pursue the broadest possible spectrum of academic and professional studies.

Finally, social services (including state rehabilitation services and federal social assistance programs) must be constantly reevaluated in light of the stories and experiences of the people for whom the services have been established. When these services are inefficient or disorganized, the delays and confusion are often compounded for people who are blind or visually impaired. Service providers should consider how people with visual impairments will physically access their offices and buildings, how and in what formats they will receive important communications, and where service recipients can turn if they experience problems. Furthermore, social services should always be established as a means to help participants enhance all dimensions of their QOL, and the eligibility requirements should not prohibit people from pursuing meaningful experiences such as productive employment or higher education. Further research into qualitative and quantitative ways to collaboratively assess individual and family QOL will help in creating truly supportive and valued social programs and services.

When we are open to learning through and from the experiences of people, we are not limited by preconceptions, established norms, or perceived impossibilities. In the actual lives of students who are blind, I encountered stories of passion, contradiction, humor, fear, and optimism – experiences that I could never have understood through test scores or clinical observations. While I continue to pursue an “instrument” for QOL studies involving people with visual impairments, I will also advocate for mixed-method evaluations and continuous participant involvement.

Stories of people with visual impairments have direct and immediate implications for shaping external supports, fostering interdependence and independence, promoting internal supports, and identifying and supporting meaningful experiences.

Even more importantly, these stories are powerful reminders that in our shared experience as human beings we have much more in common with one another than we typically recognize. Perhaps the most fitting conclusion to this dissertation can be drawn from the words of Archbishop Desmond Tutu, who explained that once we come to know one another, we realize, “You have gifts that I do not have and I have gifts that you don’t have. And you can almost imagine God rubbing God’s hands and saying, ‘Viola! That’s exactly what I wanted you to know!’” (Bisanz, 2008).

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## **APPENDIX A**

### **INTERVIEW PROTOCOLS**

#### **Interview One**

##### **Introduction**

Thank you again for taking part in this study. Once again, I want to remind you that your participation is totally voluntary, and you can ask to stop at any time.

I am interested to hear your thoughts, feelings, and experiences about what makes up a “good life,” in other words, “quality of life,” and how this has influenced you in the past. I would also like to know about what you think about quality of life and your future. I would like you to tell me about positive and negative experiences, as well as neutral experiences. For this first interview, we’ll focus on the events in your life up until now – somewhat like telling me your life story, with an emphasis on quality of life.

I have written down a few questions to help guide our conversation; however, feel free to talk about whatever is important to you.

##### **Questions:**

1. Starting with when you were young until today, tell me about times when things have gone really well in your life.
2. How about times that were especially tough in your life?
3. Tell me about friends who you like to spend time with. How did you meet? What do you do together?
4. What is a typical day like for you now? What are you studying/learning at \_\_\_\_\_ [vocational program/university/rehab center/college/etc.]?

**General probes to elicit more details:**

- What was that like for you?
- How do you mean?
- Can you please elaborate?

**Conclusion:**

Interviewer will summarize the interview and ask if the expressed meaning had been comprehended. Interviewer will provide participant with \$15 gift card.

Participants will be asked permission for the interviewer to contact them for follow-up questions and the date and time will be confirmed for Interview Two.

**Interview Two**

**Introduction:**

Thank you again for taking part in this study. Once again, I want to remind you that your participation is totally voluntary, and you can ask to stop at any time.

I am interested to hear your thoughts, feelings, and experiences about what makes up a “good life,” in other words, “quality of life,” and how this has influenced you in the past. I would also like to know about what you think about quality of life and your future. I would like you to tell me about positive and negative experiences, as well as neutral experiences. For this second interview, we’ll focus on the details of some of the events you shared and of your current experiences as a young adult, with an emphasis on quality of life.

I have written down a few questions to help guide our conversation; however, feel free to talk about whatever is important to you.

**Questions:**

1. Last time we met, you mentioned \_\_\_\_\_ [experience related during Interview One]. Can you tell me more about what that's like? (of special interest are current and prior school experiences, friendships, family, free-time, and poignant life events)
2. Tell me about the people in your life who help you when things aren't going well. What is your relationship like with them?
3. Where are your favorite nearby places to go? Tell me what it's like there.
4. Where are your least favorite places to go? Tell me what it's like there.

**General probes to elicit more details:**

- What's that like for you?
- How do you mean?
- Can you please elaborate?

**Conclusion:**

Interviewer will summarize the interview and ask if the expressed meaning had been comprehended. Interviewer will provide participant with \$15 gift card.

Participants will be asked permission for the interviewer to contact them for follow-up questions, and the date and time will be confirmed for Interview Three.

### **Interview Three**

#### **Introduction:**

Thank you again for taking part in this study. Once again, I want to remind you that your participation is totally voluntary, and you can ask to stop at any time.

I am interested to hear your thoughts, feelings, and experiences about what makes up a “good life,” in other words, “quality of life,” and how this has influenced you in the past. I would also like to know about what you think about quality of life and your future. I would like you to tell me about positive and negative experiences, as well as neutral experiences. For this final interview, we’ll focus on what you think and feel about quality of life, given the experiences and details you’ve shared in the past two interviews.

I have written down a few questions to help guide our conversation; however, feel free to talk about whatever is important to you.

#### **Questions:**

1. When you hear the words quality of life, what first comes to your mind?
2. What does it mean for you to have things going well in your life? Thinking about the times that have gone well in your life, what do you think helps things go well? Why?
3. What does it mean for you when times are tough? Thinking about the times that were especially tough in your life, what do you think are some of the reasons for tough times? Why?
4. What about the future? What will need to happen for things to go well in your life?
5. What might happen to cause tough times in the future?
6. Do you think the skills you learned in school are helping you to lead the life you want to lead? What were the most important skills you learned? What do you still want to learn?

**Conclusion:**

Interviewer will summarize the interview and ask if the expressed meaning had been comprehended. Interviewer will provide participant with \$20 gift card.

Participants will be asked for permission for the interviewer to contact them if needed for a fourth interview and to follow up with them for their feedback on the data analysis.

## APPENDIX B

### INSTITUTIONAL REVIEW BOARD APPROVAL



TEXAS TECH UNIVERSITY  
Vice President for Research

January 17, 2014

Rona Pogrud  
Ed Psychology & Leadership  
Mail Stop: 1071

Regarding: 504314 Qualitative Investigation of the Experience of Quality of Life for Young Adults Who Are Blind

Dr. Rona Pogrud:

The Texas Tech University Protection of Human Subjects Committee has approved your proposal referenced above. The approval is effective from January 17, 2014 to December 31, 2014. This expiration date must appear on all of your consent documents.

We will remind you of the pending expiration approximately eight weeks before December 31, 2014 and to update information about the project. If you request an extension, the proposal on file and the information you provide will be routed for continuing review.

Sincerely,

A handwritten signature in cursive script that reads "Rosemary Cogan".

Rosemary Cogan, Ph.D., ABPP  
Protection of Human Subjects Committee

Box 41075 | Lubbock, Texas 79409-1075 | T 806.742.3905 | F 806.742.3947 | [www.vpr.ttu.edu](http://www.vpr.ttu.edu)  
An EEO/Affirmative Action Institution

## APPENDIX C

### AUDIT TRAIL

#### Dates of Interviews

Alex	Interview 1: 4/22/2014
	Interview 2: 4/25/2014
	Interview 3: 4/25/2014
Brianne	Interview 1: 3/6/2014
	Interview 2: 3/11/2014
	Interview 3: 3/13/2014
Darik	Interview 1: 4/28/2014
	Interview 2: 4/29/2014
	Interview 3: 4/30/2014
Janessa	Interview 1: 3/11/2014
	Interview 2: 3/13/2014
	Interview 3: 3/14/2014
Martin	Interview 1: 4/15/2014
	Interview 2: 4/16/2014
	Interview 3: 4/22/2014
Tess	Interview 1: 4/25/2014
	Interview 2: 4/26/2014
	Interview 3: 4/27/2014

Interview Code: X:Y

X = Interview Number (1, 2, or 3)

Y = Paragraph number

#### Participant pseudonym Interview Code(s)

<sup>1</sup> Alex	1:11
<sup>2</sup> Alex	1:71
<sup>3</sup> Alex	1:73, 1:75
<sup>4</sup> Alex	1:17
<sup>5</sup> Alex	3:86
<sup>6</sup> Brianne	2:222
<sup>7</sup> Brianne	1:85-90
<sup>8</sup> Brianne	1:96
<sup>9</sup> Brianne	1:42-46, 2:234-237
<sup>10</sup> Brianne	2:2-14
<sup>11</sup> Brianne	1:204
<sup>12</sup> Darik	1:4
<sup>13</sup> Darik	1:4
<sup>14</sup> Darik	1:6
<sup>15</sup> Darik	1:24
<sup>16</sup> Darik	1:52
	2:84
<sup>17</sup> Darik	2:94

## Audit Trail Continued

Participant pseudonym	Interview Code(s)
<sup>18</sup> Janessa	1:86
<sup>19</sup> Janessa	1:4, 1:14, 1:50, 1:52 2:148
<sup>20</sup> Janessa	2:80, 2:98
<sup>21</sup> Janessa	1:80
<sup>22</sup> Janessa	1:110, 1:142, 2:17-20
<sup>23</sup> Janessa	1:34, 2: 34
<sup>24</sup> Martin	1:56
<sup>25</sup> Martin	1:5
<sup>26</sup> Martin	1:20, 1:26-28
<sup>27</sup> Martin	1:94, 1:128
<sup>28</sup> Martin	2:19-24
<sup>29</sup> Martin	2:48
<sup>30</sup> Tess	1:12
<sup>31</sup> Tess	1:50
<sup>32</sup> Tess	1:8-10
<sup>33</sup> Tess	1:68-72
<sup>34</sup> Tess	1:16, 1:40, 1:80-84, 1:180
<sup>35</sup> Tess	1:118
<sup>36</sup> Tess	1:40
<sup>37</sup> Tess	1:42
<sup>38</sup> Darik	2:94
<sup>39</sup> Brianne	3:137
<sup>40</sup> Martin	3:6
<sup>41</sup> Tess	3:68
<sup>42</sup> Alex	1:99
<sup>43</sup> Darik	3:60
<sup>44</sup> Brianne	3:43
<sup>45</sup> Martin	3:90-92
<sup>46</sup> Janessa	2:98
<sup>47</sup> Alex	1:93, 3:66, 3:68
Brianne	2:175,
Darik	1:6, 1:10, 2:26, 3:26,
Janessa	1:2, 3:78, 3:81
Martin	2:178
Tess	1:12, 1:116, 1:122, 1:139, 2:76, 2:80, 2:143, 3:54
<sup>48</sup> Brianne	2:175
<sup>49</sup> Janessa	1:2
<sup>50</sup> Martin	1:120
<sup>51</sup> Tess	2:46
<sup>52</sup> Tess	2:84
<sup>53</sup> Tess	1:26
<sup>54</sup> Janessa	1:18
<sup>55</sup> Alex	1:11
<sup>56</sup> Alex	1:25
<sup>57</sup> Alex	1:163, 3:12
<sup>58</sup> Darik	1:50, 2:96
<sup>59</sup> Darik	2:96
<sup>60</sup> Brianne	1:102



## Audit Trail Continued

Participant pseudonym	Interview Code(s)
<sup>61</sup> Brianne	1:105-109
Alex	2:92
<sup>62</sup> Tess	1:200
<sup>63</sup> Martin	1:167
<sup>64</sup> Martin	1:180
<sup>65</sup> Janessa	3:54
<sup>66</sup> Brianne	2:132
<sup>67</sup> Darik	2:16
<sup>68</sup> Alex	1:127
<sup>69</sup> Brianne	2:249
<sup>70</sup> Martin	3:132
<sup>71</sup> Tess	1:176
<sup>72</sup> Tess	1:204
<sup>73</sup> Alex	1:173
<sup>74</sup> Brianne	1:323
<sup>75</sup> Darik	3:10
Tess	2:40-44
<sup>76</sup> Darik	3:10
<sup>77</sup> Alex	1:167
<sup>78</sup> Tess	3:86
<sup>79</sup> Janessa	2:78
<sup>80</sup> Martin	1:190
<sup>81</sup> Darik	2:14
<sup>82</sup> Tess	2:52
<sup>83</sup> Alex	1:121
<sup>84</sup> Brianne	1:98, 2:134
<sup>85</sup> Janessa	1:150
<sup>86</sup> Darik	3:6
<sup>87</sup> Martin	2:16
<sup>88</sup> Darik	1:4
<sup>89</sup> Brianne	2:251
<sup>90</sup> Janessa	2:66
<sup>91</sup> Tess	1:122
<sup>92</sup> Tess	1:96, 2:139
<sup>93</sup> Alex	1:187
<sup>94</sup> Tess	2:143
Alex	1:157
<sup>95</sup> Tess	2:143
<sup>96</sup> Janessa	1:64
<sup>97</sup> Brianne	1:227
<sup>98</sup> Tess	3:12
<sup>99</sup> Martin	2:24
<sup>100</sup> Janessa	3:56
<sup>101</sup> Darik	1:26
<sup>102</sup> Alex	3:112
<sup>103</sup> Brianne	3:187-206
<sup>104</sup> Tess	2:162-172
<sup>105</sup> Tess	1:200
<sup>106</sup> Brianne	189-200

## Audit Trail Continued

Participant pseudonym	Interview Code(s)
<sup>107</sup> Brianne	1:191
<sup>108</sup> Tess	3:40
<sup>109</sup> Tess	1:12
<sup>110</sup> Darik	3:14
<sup>111</sup> Brianne	3:15
<sup>112</sup> Janessa	1:158
<sup>113</sup> Martin	3:8
<sup>114</sup> Alex	3:34
Brianne	1:155, 1:354-359
Darik	2:30
<sup>115</sup> Tess	3:16
<sup>116</sup> Alex	1:141
<sup>117</sup> Darik	2:94
<sup>118</sup> Janessa	2:28
<sup>119</sup> Martin	3:134
<sup>120</sup> Tess	1:92
<sup>121</sup> Tess	3:52, 3:60
<sup>122</sup> Tess	3:52
<sup>123</sup> Brianne	1:299
<sup>124</sup> Alex	1:131, 1:139, 2:70, 3:66, 3:122-134
Janessa	2:72
Martin	3:152
<sup>125</sup> Alex	3:124
<sup>126</sup> Alex	3:126
<sup>127</sup> Alex	1:17, 3:46
<sup>128</sup> Darik	3:34
<sup>129</sup> Brianne	1:216-224
<sup>130</sup> Martin	2:76
<sup>131</sup> Martin	2:88-90
<sup>132</sup> Janessa	2:152
<sup>133</sup> Alex	1:96
Darik	1:60
<sup>134</sup> Alex	1:96
<sup>135</sup> Brianne	1:345
<sup>136</sup> Tess	1:88
<sup>137</sup> Alex	2:96
Darik	2:106
<sup>138</sup> Alex	2:96
<sup>139</sup> Tess	1:16
<sup>140</sup> Martin	3:18
<sup>141</sup> Darik	3:20
<sup>142</sup> Darik	2:46
<sup>143</sup> Alex	2:92
<sup>144</sup> Tess	1:128
<sup>145</sup> Martin	1:182
<sup>146</sup> Alex	3:71
<sup>147</sup> Alex	2:54
<sup>148</sup> Janessa	1:60
<sup>149</sup> Janessa	3:60

## Audit Trail Continued

Participant pseudonym	Interview Code(s)
<sup>150</sup> Darik	3:12
<sup>151</sup> Martin	2:166-168
<sup>152</sup> Tess	1:200
<sup>153</sup> Tess	3:30
<sup>154</sup> Darik	3:10
<sup>155</sup> Martin	2:202
<sup>156</sup> Brianne	2:25
<sup>157</sup> Tess	1:38
<sup>158</sup> Darik	1:32
<sup>159</sup> Brianne	1:71, 2:82
Janessa	1:52, 1:84, 1:90, 1:93, 3:40
Tess	1:84, 3:42
<sup>160</sup> Martin	3:42
<sup>161</sup> Tess	3:36
<sup>162</sup> Darik	1:40
<sup>163</sup> Darik	1:10
<sup>164</sup> Alex	3:2
<sup>165</sup> Alex	3:106
<sup>166</sup> Brianne	3:34-38
<sup>167</sup> Janessa	2:10
<sup>168</sup> Darik	3:72
<sup>169</sup> Tess	3:44
<sup>170</sup> Tess	3:20
<sup>171</sup> Tess	2:134-136
<sup>172</sup> Tess	3:30
<sup>173</sup> Brianne	1:326-329
<sup>174</sup> Brianne	1:172
<sup>175</sup> Martin	1:38
<sup>176</sup> Alex	1:13
<sup>177</sup> Alex	1:85
<sup>178</sup> Martin	1:32
Janessa	2:148
<sup>179</sup> Janessa	2:148
<sup>180</sup> Darik	1:32
<sup>181</sup> Tess	1:152
<sup>182</sup> Brianne	3:170
<sup>183</sup> Alex	1:167
<sup>184</sup> Darik	3:70
<sup>185</sup> Martin	3:128
<sup>186</sup> Tess	1:140
<sup>187</sup> Brianne	1:168
<sup>188</sup> Alex	1:183
<sup>189</sup> Alex	1:143
<sup>190</sup> Tess	3:56
<sup>191</sup> Brianne	2:137
<sup>192</sup> Janessa	1:152
<sup>193</sup> Darik	2:26
<sup>194</sup> Brianne	2:205-225
Janessa	3:56

## Audit Trail Continued

Participant pseudonym	Interview Code(s)
Martin	3:72
<sup>195</sup> Brianne	2:205-225
<sup>196</sup> Brianne	2:64
<sup>197</sup> Martin	2:63-68.
<sup>198</sup> Alex	1:103-109
<sup>199</sup> Alex	2:116-118
<sup>200</sup> Martin	2:46
<sup>201</sup> Darik	1:20
<sup>202</sup> Tess	3:66
<sup>203</sup> Brianne	2:133-134
<sup>204</sup> Martin	1:200
<sup>205</sup> Darik	1:24
<sup>206</sup> Darik	1:24
<sup>207</sup> Alex	1:119
<sup>208</sup> Martin	1:47-54, 2:92-93
<sup>209</sup> Darik	3:26, 3:18
<sup>210</sup> Janessa	1:54
<sup>211</sup> Brianne	2:306
<sup>212</sup> Tess	3:16
<sup>213</sup> Tess	1:92
<sup>214</sup> Alex	1:35
<sup>215</sup> Martin	3:71-78
<sup>216</sup> Darik	2:84
<sup>217</sup> Darik	3:24
<sup>218</sup> Brianne	1:68
<sup>219</sup> Janessa	1:54
<sup>220</sup> Tess	2:162, 3:70
<sup>221</sup> Darik	1:46
<sup>222</sup> Brianne	1:303
<sup>223</sup> Darik	2:2
<sup>224</sup> Alex	2:60, 2:82, 2:110, 3:86, 3:90, 3:104
<sup>225</sup> Tess	2:40
<sup>226</sup> Darik	3:10
<sup>227</sup> Brianne	1:313
<sup>228</sup> Alex	1:91
<sup>229</sup> Darik	3:84
<sup>230</sup> Darik	2:96
<sup>231</sup> Martin	3:104
<sup>232</sup> Tess	3:34
<sup>233</sup> Janessa	1:52
<sup>234</sup> Darik	2:106
<sup>235</sup> Brianne	2:222
<sup>236</sup> Janessa	2:14
<sup>237</sup> Tess	2:76
<sup>238</sup> Darik	1:69-72
<sup>239</sup> Alex	1:141
<sup>240</sup> Tess	3:26
<sup>241</sup> Tess	3:8
<sup>242</sup> Alex	3:70

## Audit Trail Continued

Participant pseudonym	Interview Code(s)
<sup>243</sup> Janessa	3:16
<sup>244</sup> Martin	3:10-12
Tess	3:12
<sup>245</sup> Janessa	1:52, 2:62, 2:34, 2:128, 2:141
<sup>246</sup> Martin	1:164
<sup>247</sup> Martin	3:208
<sup>248</sup> Alex	3:42
<sup>249</sup> Tess	3:58
<sup>250</sup> Janessa	3:5-6
<sup>251</sup> Darik	2:106
<sup>252</sup> Tess	3:42
<sup>253</sup> Brianne	2:100
<sup>254</sup> Brianne	2:112
<sup>255</sup> Martin	1:118
<sup>256</sup> Martin	1:30
<sup>257</sup> Alex	1:101
<sup>258</sup> Janessa	1:84
<sup>259</sup> Darik	1:16
<sup>260</sup> Brianne	2:233
<sup>261</sup> Brianne	2:29
<sup>262</sup> Tess	1:16
<sup>263</sup> Tess	2:80
<sup>264</sup> Tess	1:122