

SOCIAL PARTICIPATION: PERSPECTIVES ON THE LIVED EXPERIENCES OF  
ADOLESCENTS WHO HAVE VISUAL IMPAIRMENTS

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## ABSTRACT

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### SOCIAL PARTICIPATION: PERSPECTIVES ON THE LIVED EXPERIENCES OF ADOLESCENTS WHO HAVE VISUAL IMPAIRMENTS

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Social participation, “the interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends” (Gillen & Boyt Schell, 2014, p. 607), is identified as an important occupation within the domain of occupational therapy (AOTA, 2014). Social participation includes engagement at the community, family, and peer levels. However, little information is available in occupational therapy literature regarding social participation issues of adolescents with visual impairment. This dissertation study explores the perceptions of adolescent with visual impairment and their parents regarding their experiences of social participation. The Children’s Assessment of Participation and Enjoyment and the Preferences for Activities of Children were used to compare the social activity patterns of five adolescents who have visual impairments with five typically sighted adolescents. The assessments were administered in interview format. Five visually impaired teens’ perceptions of their social participation experiences and their meaning were explored through semi-structured in-depth interviews. Three parents of teen participants shared their perceptions of their own and their children’s social participation experiences

through semi-structured in-depth interviews. Case-by-case analysis and cross-case analysis assisted in identifying emerging themes: “protection versus freedom,” “concern about social participation,” and “barriers and supports to social participation.” Sub-themes within “barriers” were identified as “lack of access to information” and “mobility.” Sub-themes of supports were identified as “vision-related specialized services” and “importance of team activities.” Implications for occupational therapy include the need to develop a knowledge and evidence base for intervention in the area of social participation for adolescents who have visual impairments. In order to address the challenges to social participation described by the participants, more research is needed. Questions remaining to be answered include: “How can occupational therapists support social participation of adolescents who have visual impairments?” “How can occupational therapists contribute to effective community mobility of adolescents who have visual impairments?” “How can occupational therapists support and collaborate with other professionals who address the needs of adolescents with visual impairments?” Additional research is needed to ensure the efficacy of interventions that might be used.

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## CHAPTER I

### STATEMENT OF PROBLEM AND SPECIFIC AIM

#### **Introduction**

The goal of occupational therapy intervention with children who are visually impaired can be framed as enabling them to function optimally in the sighted world. Addressing social participation is central to this intervention. Social participation is defined as “the interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends” (Gillen & Boyt Schell, 2014, p. 607) and is identified in the Occupational Therapy Practice Framework (AOTA, 2014) as an important occupation within the professional domain.

Social participation difficulties experienced by children, adolescents and young adults who have visual impairments are well documented (Caballo & Verdugo, 2007; Sacks & Wolfe, 2006; Sacks, Wolfe, & Tierney, 1998; Sacks & Wolfe, 2006; Wolfe & Sacks, 1997). Although visually impaired adolescents tend to function at the same level academically as their sighted peers, they tend to have smaller social networks, participate in a narrower range and more passive selection of activities, and may have more difficulty maintaining close friend relationships than those peers (Kef, 1997; MacCuspie, 1996; Pinguart & Pfeiffer, 2013; Wolfe & Sacks, 1997).

Social participation involves function in a variety of settings, including neighborhood, school, and wider community as well as interaction with family and friends (AOTA, 2014). The skills needed for successful social participation, including social competence, are typically acquired as a developmental process. Severe visual impairment has the potential to affect all areas of development. Motor and language development in particular may be affected along with the ability to access information in the environment through vision. Motor milestones involved in moving into space are often developed later in children with congenital severe visual impairment than in typically sighted children (Brambring, 2006; Celeste, 2002; Troster, Hecker, & Brambring, 1993; Troster, Hecker, & Brambring, 1994). Because children develop an understanding of their ability to be independent and control the environment through movement and interaction with the environment, early motor delays may affect social interactions. Skills and concepts affected can include understanding social distances, knowledge of how to approach a group of children, and a sense of personal agency. It is also well documented that many children with severe visual impairments often experience delays in language development which is basic to interacting with one's environment and understanding the world (Andersen, Dunlea & Kekelis, 1984; Brambring, 2007; James & Stojanovik, 2007; Tadić, Pring, & Dale, 2010). In a classic study, MacCuspie (1996) found that young visually impaired children tend to have fewer friends and fewer interactions than their sighted peers. In addition, when vision is compromised, a child may not notice or be able to interpret nonverbal communication

cues, which can influence behavior in social situations. All these factors can lead to delay or difficulty in developing social competence and which can then negatively influence social participation.

Occupational therapists may encounter young visually impaired children and adolescents through a variety of practice venues including early childhood intervention programs, hospitals, schools, and low vision clinics. The focus of therapy is often dependent on the setting; however, the end goal of any therapy provided is to enable engagement with one's environment and the people in it, the definition of social participation. There is a dearth of literature in occupational therapy addressing the issue of social participation of visually impaired adolescents. We do not yet have a unique occupational therapy knowledge or evidence base from which to intervene.

### **Statement of Problem**

Although social participation is an important aspect of occupational performance for children and teens with visual impairment and affects their successful transition to adulthood (Cmar, 2013; Wolffe & Kelly, 2011), not enough is known about social participation in this population to provide a basis for occupational therapy intervention. More information is needed about the ways in which visually impaired adolescents and families experience their social participation.

### **Statement of Purpose**

The purpose of this study is to advance understanding of the lived experience of adolescents who are visually impaired and their parents. The Children's Assessment of

Participation and Enjoyment (CAPE) and the Preferences for Activities of Children (PAC) assessments were used to identify and describe commonalities and differences in social participation patterns of five adolescents with visual impairments compared to those of five age and gender matched typically sighted adolescents. This was followed by in-depth semi-structured interviews with the same visually impaired adolescent participants to explore their experiences of social participation. Lastly, in-depth semi-structured interviews with three of the visually impaired adolescents' parents explored their perception of their adolescents' experiences. Data from interviews were analyzed via case-by-case and cross-case analyses to determine emergent themes.

The following research questions are addressed in this study:

1. What differences exist in patterns of participation between typically sighted and visually impaired adolescents as measured by the CAPE and PAC?
2. What meaning does social participation have for visually impaired adolescents?
3. How do visually impaired adolescents experience supports and barriers to social participation?
4. How do qualitative data regarding visually impaired adolescents' experiences of social participation compare with the findings of the CAPE and PAC?
5. What is the meaning to parents of their visually impaired adolescents' social participation?
6. How do parents' perceptions of social participation differ from the perceptions of adolescents?

## **Researcher's Stance**

As an Occupational Therapist, Certified Orientation and Mobility Specialist, and Certified Low Vision Therapist, I have provided services in various capacities to children, adolescents, and adults for more than 30 years. My first long-term professional occupational therapy position was school-based, within a program for visually impaired children. During my time in the public school setting, I was privileged to work with and learn from many highly skilled and specialized vision teachers, Certified Orientation and Mobility Specialists, and occupational therapists. My experience with these professionals inspired me to go on to earn my master's degree in special education with certification in orientation and mobility. As a Certified Orientation and Mobility Specialist, I learned more about low vision issues and how severe visual impairment affects development. This led me to find work in low vision clinics and to earn my certification as a low vision therapist.

During my years working with this population I have been surprised by how little information about working with visually impaired children and adolescents has been generated by the profession of occupational therapy. As an occupational therapist, I felt I had much to contribute to the traditional blindness/low vision team, but I had little data from my profession on which to draw. As occupational therapists became more actively involved in working with patients with low vision (as Medicare funding for services became available in the early 1990s), most occupational therapists in the field focused on adult services. Of note, even AOTA specialty certification in low vision is designed for



adult services, with experience working with adults listed as an eligibility requirement. Given these events, I developed a commitment to add to the occupational therapy evidence base for providing services to children and adolescents with visual impairments. This dissertation research is an attempt to fulfill that commitment. As experts in adaptation across the lifespan, occupational therapists should be strong members of any team addressing the needs of children and adolescents who have visual impairments. In order to do this, we have to develop an evidence base from which to work and from which to collaborate with other skilled professionals.

## CHAPTER II BACKGROUND AND SIGNIFICANCE

### **Context**

The International Classification of Functioning, Disability and Health (ICF) defines participation as “a person’s involvement in a life situation” (WHO, 2002) and identifies participation as an important indicator of health and well-being. The purpose of occupational therapy intervention is to enable participation (AOTA, 2014). Social participation within occupational therapy is defined as “the interweaving of occupations to support desired engagement in community and family activities as well as those involving peers and friends” (Gillen & Boyt Schell, 2014, p. 607).

The achievement of social developmental milestones is an important basis for social participation and engagement. In typically developing children, social skills and awareness emerge in generally predictable sequences. For instance, by one month, a child prefers looking at human faces to abstract images, by three months the child begins to develop a social smile, and by two years the child is able to take turns with friends. This developmental progression continues through the teen years. In early teens, children begin to spend less time with their families and more with their peers. As they continue to mature, their relationships with others outside the immediate family increase in importance and help them define themselves (Vroman, 2013).

The progression of development of social and other milestones may be delayed by the presence of a disability, including visual impairment, and this may affect social participation (Mandich & Rodger, 2007). Children with disabilities may demonstrate different patterns of social participation than their non-disabled peers. Findings of studies in social participation of children with disabilities indicate that this population has a narrower scope of activities and less frequency of participation than non-disabled peers (Coster et al., 2013; Engel-Yeger, Jarus, Anaby, & Law, 2009). Coster et al. (2013) reported results of a study using the Participation and Environment Measure for Children and Youth (PEM-CY) to compare participation of children with and without disabilities at school. A wide range of disabilities was represented in the study, including developmental delay, orthopedic impairment, autism spectrum disorder, hearing impairment, and visual impairment, among others. Coster et al. found that parents of children with disabilities reported their children had less frequent participation in school organizations and clubs, and less frequent meetings with peers than did parents of children with no disabilities. Parents of children with disabilities also reported more barriers to social participation than did parents of children without disabilities. Engel-Yeger, Jarus, Anaby, and Law (2009) used the Children's Assessment of Participation and Enjoyment (CAPE) to compare the social participation patterns of teens with and without cerebral palsy. They found that those with cerebral palsy reported a narrower range of activities and less frequent participation than those without cerebral palsy. Engel-Yeger and Hamed-Dahar (2013) likewise compared the out- of- school activities of

children with visual impairments, children with hearing impairments, and typical peers. Using the CAPE, they found that the children with visual impairments and children with hearing impairments participated in fewer activities and with less frequency than did their typical peers.

Social participation is identified in research related to individuals with visual impairments as important for successful adolescent-to-adult and school-to-post-school transition (Agran, Hong, & Blankenship, 2008; Luft, Rumrill, Snyder, & Hennessey 2001; McDonnall & Crudden, 2009; Shaw, Gold, & Wolffe, 2007). It is important, therefore, to understand social participation patterns in adolescents in order to design effective interventions which may help lead to successful overall function, including transition to adult life.

### **Early Effects of Visual Impairment**

Children and teens with visual impairments often experience difficulty or limitations in social participation and these limitations typically occur across contexts including school, home, and community. Visual impairment can affect the progression of development in all domains, including motor, language, and communication development, which in turn, may affect social interaction. The severity of visual impairment as well as whether the visual impairment is congenital or acquired is important, as congenital impairment and visual impairment of greater severity affect development most globally (Bambring, 2006; Hatton, Bailey, Burchinal, & Ferrell, 1997; Tsai, Meng, Wu, Jang & Su 2013; Wolffe, 2006a).

As movement is one way in which children learn about the world, their own abilities, experience independence and control, and communicate with others, it may be expected that when motor development is affected, social interactions may be affected as well. Several researchers have investigated the motor skills of blind children. Most have found that blind and severely visually impaired children acquire static milestones near the same time as their sighted peers but demonstrate delay in skills such as changing position or moving into space (Adelson & Fraiberg, 1974; Brambring, 2006; Celeste, 2002; Ferrell, 1998; Troster et al., 1993; Troster et al., 1994).

Research also suggests that visually impaired infants and children often have challenges developing language and communication skills (James & Stojanovik, 2006; Tadić, Pring, & Dale, 2010) and subsequently difficulty in interaction with others. Tadić, Pring and Dale (2010) compared language abilities of 15 children with visual impairment to those of 26 typically developing peers. The children with visual impairment demonstrated difficulty with pragmatic language skills. They scored higher on standardized tests of language function than their typical peers but lower on tests of use of language for social purposes. Young children with visual impairment may have difficulty with attachment, as they lack eye contact typically used to establish connection, shared visual attention and social cues and because parents may misinterpret their responses (Fraiberg, 1970, 1975, 1977; Lewis & Wolffe, 2006; Sacks, 2006). Studies of parent-child interactions show that parents of young children who are blind tend to use more directives than engagement in reciprocal conversation, which may affect

development of language for social use (Adenzato, Ardito, & Izard, 2006; Kekelis & Prinz, 1996). Erin (2006) also points out that sighted children learn some social conventions incidentally, through observation. They notice social proximity, body language, facial expressions, and other clues in response to their own and others' behaviors. Children with visual impairments do not have access to the same information as their typically sighted peers; they may miss or misinterpret these important clues.

### **Social Participation Challenges of Visually Impaired Children and Teens**

Children with visual impairments have been found to have difficulty establishing and maintaining relationships. MacCuspie (1996) reported that children with visual impairment tend to have fewer friends than sighted children. Young visually impaired children tend to initiate interactions less frequently and with less success than their sighted peers (Crocker & Orr, 1996; Kekelis, 2006; MacCuspie, 1992; McGaha & Farran, 2001; Sacks, 2006). Killegrew and Kroksmark (1999) reported a case study of time use and location carried out through observation by an occupational therapist. They found that a visually impaired seven year old spent most of his school day in individual activities.

These challenges in social participation continue in adolescence. Wolffe and Sacks (1997) reported results from Social Network Pilot Project, conducted between 1993 and 1996. The study consisted of two parts, one quantitative and one qualitative. Study One compared, through quantitative data, the involvement in academic, daily living and person care, recreation and leisure, and vocational activities of three groups

(functionally blind, low vision, and sighted adolescents, 15-21 years old). Data were collected through questionnaires and time diaries. In addition, parents' expectations for their adolescents' involvement were compared to the adolescents' involvement level and frequency. Results showed that visually impaired teens tended to have a narrower scope of activities and spent more time alone and in passive activities than did their sighted peers. In addition, while most participants in the study had paid work experience, the sighted participants had found their own jobs while the jobs held by participants with visual impairments were found by adults in their lives. Study Two of the Social Network Pilot Project (Sacks & Wolffe, 1998) was a qualitative study, involving three visually impaired adolescents from Study One. Data about the frequency and quality of involvement in activities were collected through eight observations of each participant over a four month period, in the areas addressed by Study One. Compared to Study One sighted participants, the three adolescents in this study needed more time for academics, participated in less community mobility, had more limited vocational experiences, preferred being with visually impaired rather sighted peers, and had fewer opportunities for choice-making than sighted peers. Gold, Shaw, and Wolffe (2010), in contrast to some of these findings, found that participants with visual impairment reported that most of their friends were sighted. Kroksmark and Nordell (2001) studied the leisure-time activities of four visually impaired and two typically sighted adolescents. Participants maintained diaries in which they noted the time, location and people involved in their activities, for six days during the summer and six days during fall or winter. The

investigators found the adolescents with visual impairments participated more in passive activities, engaged in fewer types of activities and participated in more formal activities than their sighted peers. Salminen and Karhula (2014) used the Canadian Occupational Performance Measure, as well as in-depth interviews, with 14 adolescents with visual impairments and their parents to explore the adolescents' social participation challenges. They identified mobility, making friends and leisure and recreation areas as primary challenges.

The social networks of adolescents with visual impairments tend to be a bit smaller than those of their typically sighted peers and parents are their most important source of support (Kef, 1997; Sacks et al., 1998). Huurre and Aro (1998) found that visually impaired adolescents in their study had fewer friends and reported feelings of loneliness and difficulty making friends more often than sighted adolescents. Other and some more recent studies indicate different findings. Rosenblum (1997) found that adolescents who were visually impaired were able to establish and maintain best-friend relationships. Rosenblum (2000) reported that her participants related having reciprocal relationships with their best friends. Gold, Shaw, and Wolffe (2010), in their study of Canadian youths with visual impairments, found that most participants reported having five or more close friends. Most of the friends were sighted and most of the participants used technology to keep in touch with friends.

Findings of research related to social participation of adolescents with visual impairment show that visually impaired adolescents tend to have a narrower range of



activities in which they participate, have fewer people with whom they carry out activities, tend more toward solitary and passive activities, and may have more difficulty establishing and maintaining interactions than their sighted peers (Huure & Aro, 1998; Kef, 1997; Kef & Bos, 2006; Sacks & Wolffe, 1998; Sacks et al., 1998; Salminen & Karhula, 2014; Wolffe & Sacks, 1997). There are many issues related to these challenges. While sighted teens learn about the subtleties of social interaction and rules incidentally for instance, young girls may watch how older girls move, smooth their skirts, or flip their hair, and the responses they elicit, the presence of visual impairment may interfere with the adolescent's access to these forms of social information (Wolffe, 2006b). Important knowledge of "in-crowd" current styles of dress and grooming, understanding of nonverbal communication including their own and others' body language and facial expressions, and gaining peer-comparable experience such as driving and autonomy in mobility, among other areas, can be affected by the inability to gather accurate visual information or see at all (Wolffe, 2006b). This can influence interactions between visually impaired teens and their peers, the desire for social participation and the opportunities for social participation (Wolffe, 2006b).

**Transition to adulthood and post-school life.** Data from the Second National Longitudinal Transition Study (NTLS2), a federally mandated outcome study of special education program services, indicate that employment and independent living rates among young adults with disabilities are lower than those of individuals without disabilities (Wagner, Newman, Cameto, & Levine, 2005). Individuals who are visually

impaired are employed at lower rates than their sighted peers (Connors, Curtis, Wall Emerson, & Dormitorio, 2014; McDonnall, 2011; McDonall & O'Mally, 2012) even when educational levels are comparable to or higher than those of the general population (Kirchner & Smith, 2005; McDonnall, 2010; Shaw et al., 2007; Wagner et al., 2005).

The need to address social participation for transition-aged adolescents is underscored by the many studies identifying predictors of successful post school independent living and employment. All involve factors related to social participation. McDonnall and O'Mally (2012) and McDonnall (2011) found that having multiple work experiences was more of a predictor of future employment than simply having paid work experience. McDonnall (2011) posits that having multiple work experiences may result in larger social networks and so may lead to more numerous job leads. However, adolescents with visual impairments are less likely to engage in paid work during high school or in work-based experiences at all, than students who are typically sighted (Sacks et al., 1998; Wagner et al., 2005; Wolffe, 2006a). In addition, McDonnall and O'Mally (2012) found that experience finding one's own job independently is a predictor of future employment. This is important in light of Wolffe and Sacks' (1998) finding that adolescents with visual impairment typically do not find their own jobs but rely on others for job contacts (Wolffe, 2006a). The presence of good travel (O&M) skills has also, been identified as a predictor of future employment (Cmar, 2015; McDonnall, 2011) along with ease of transportation (McDonnall, 2011). Academic competence and

completion of a post-secondary program has been identified as a predictor of successful transition as well (Connors et al., 2014; McDonnall & Crudden, 2009).

Wolffe and Kelly (2011) found that instruction in areas of the Expanded Core Curriculum (ECC) is related to positive transition outcomes for adolescents who are visually impaired. The ECC is set of nine disability-specific adaptive skill areas identified by experts in the education of children who are visually impaired as necessary, in addition to the general school curriculum, to successful school and post-school life (Hatlen, 1996; Huebner, Merk-Adam, Stryker, & Wolffe, 2004). These areas are a) compensatory skills, b) orientation and mobility, c) assistive technology, d) independent living skills, e) social interaction, f) recreation and leisure skills, g) sensory efficiency skills, h) career education, and i) self-determination skills. All of these are skills that either directly involve or enable social participation. Wolffe and Kelly (2011) found several relationships among ECC areas and positive transition outcomes. Botsford (2013) in a meta-analysis of research that used NTLS2 data also found a positive effect for social skills on transition outcomes.

The ability to engage in a way that is meaningful to the individual and in which societal expectations are met is an indication of successful transition. Social participation patterns may be the basis for or impediment to successful transition from school to post-school life and adulthood. Social participation is an area that must be addressed by occupational therapists working with adolescents who have visual impairments.

### **Frame of Reference: Occupational Adaptation**

This study is situated within the Occupational Adaptation (OA) frame of reference. The OA framework is quite complex, involving systems and subsystems, processes and multiple sub-processes. The information presented here is meant as an overview only, rather than a detailed analysis of OA.

OA explains how adaptation occurs as a result of interaction between the person and the environment. The person, comprised of sensorimotor, cognitive, and psychosocial elements, has an innate desire to master challenges. The three elements have a role in every response but sometimes one or the other dominates, according to the needs of the situation. The balance of the elements at any time is called the adaptation gestalt. The desire for mastery is influenced by the person's occupational role expectations. Occupational role expectations develop from both internal (experiential) and external (environmental) expectations. (Schkade & McClung, 2001)

The environment, or context, in which an occupational role is carried out, is called the occupational environment. Occupational environments include physical, social, and cultural influences, or subsystems. These subsystems create external occupational role expectations. Just as the person has a desire for mastery, the occupational environment requires mastery. The interaction of the desire for mastery and the requirement, or demand, for mastery results in a press for mastery. The press for mastery can be described as a need for a response. The press for mastery becomes the occupational challenge. The occupational challenge results from the person's occupational roles and

internal and external role expectations. Occupational role expectations are the reason a person produces an adaptive response. Adaptive responses arise from the adaptive response generation sub-process.

The adaptive response generation sub-process enables the person to anticipate the outcome of his or her response (Schkade & McClung, 2001) and is comprised of the adaptive response mechanism and the adaptation gestalt. The adaptive response mechanism has three elements: adaptation energy (primary and secondary), adaptive response modes (existing, modified, or new), and adaptive response behaviors (primitive, transitional, and mature) (Schkade & McClung, 2001). Adaptation energy refers to the energy expended when addressing an occupational challenge. Primary energy is intense, focused, and quickly depleted; secondary energy is lower intensity, uses little attentive effort, and is more enduring than primary. Most efficient is an interplay between the two. Adaptive response modes are patterns of responses. Typically, a person relies on patterns he or she has already developed when first encountering an occupational challenge. If the existing mode does not work well, it may be modified. If modified patterns of response are not successful, new modes must be developed for successful outcome. Adaptive response behaviors are the “types of behavior we use in attempting to respond adaptively...” (Schkade & McClung, 2001, p. 41). Primitive adaptive response behaviors are hyperstable, or inflexible. They are typically used when a person is under stress and are considered normal when used as a temporary response. When they are used for long periods and to the exclusion of other possible responses, they can interfere with

adaptation. Transitional adaptive response behaviors tend to be hypermobile; they are “highly variable, very active” and not well directed (Schkade & McClung, 2011). As the label suggests, they are often a segue from primitive to mature adaptive behaviors.

Mature adaptive response behaviors are regulated and goal-directed. The adaptive gestalt has already been introduced. The balance of person elements (sensorimotor, cognitive, psychosocial) can be changed by the person to allow the one or the other element to dominate, as required by the particular occupational challenge. These processes and elements of the adaptive response generation sub-process produce an occupational response.

The person evaluates his or her response after it is carried out, checking for efficiency, effectiveness and satisfaction to self and others. (DeGrace, 2007; Schkade & McClung, 2001) The sense of satisfaction to self and others in terms of the occupational role demands is called relative mastery. Relative mastery is experiential rather than objective. It allows the person to be the agent of change in his or her own life, by evaluating the outcome of his or her responses and making adjustments as needed. The occupational response, once evaluated, becomes integrated within the person. Depending on the results of self-evaluation, the person may decide to adjust responses in the future to achieve better results (occupational adaptation), may decide to make no changes (homeostasis), or may continue with the same response even if it does not produce positive results (dysadaptation). In addition to self-evaluation, the person receives

feedback from each subsystem of the occupational environment. The feedback becomes part of the context (Schkade & McClung, 2001).

Important for intervention are some central ideas and assumptions of the OA frame of reference. First, OA posits that improvement in functional skill does not automatically result in occupational adaptation (Schultz & Schkade, 1992). It is acknowledged that discrete skills are an important component of function and they are considered in terms of occupational readiness. In addition, OA views the patient or client as the agent of change. Within an OA frame of reference, the therapist's role is one of facilitator, "helping the person to desire engagement and experience relative mastery with occupational challenge" (Shultz & Schkade, 1992). The OA frame of reference is concerned with internal as well as external processes. The outcome is the ability to monitor one's own internal state and context in which one is functioning, to self-regulate and adjust strategies as needed. This view seems particularly useful in working with adolescents as they are developing autonomy, learning strategies for self-determination, and exploring their own identities.

### **Significance of Study**

In occupational therapy, social participation is viewed as an important occupation to be addressed. Little information is available in occupational therapy literature regarding social participation of adolescents who are visually impaired. This research study is intended to add to the understanding of issues and provide evidence for occupational therapy intervention for this population.

CHAPTER III  
METHODOLOGY

**Design**

This study was designed to use a mixed methods approach. A descriptive research design was used in Part One to answer the question, “What differences exist in patterns of participation between sighted and visually impaired adolescents, as measured by the CAPE and PAC?” In Part Two, a phenomenological approach was used to answer, “What meaning does social participation have for visually impaired adolescents? How do visually impaired adolescents experience supports and barriers to social participation? How do qualitative data regarding visually impaired adolescents’ experiences of social participation compare with the findings of CAPE and PAC?” Creswell (2007) indicates that phenomenology is an appropriate method for describing the common experiences individuals have with a particular phenomenon. Part Two of the study was meant to examine the experiences of social participation that individual adolescents who are visually impaired have in common with each other. Current literature from the traditional blindness/visual impairment education and rehabilitation field identifies limitations in social participation for adolescents and young adults with visual impairment (McDonnell, 2010; Pinguart & Pfeiffer, 2011; Sacks & Wolffe, 1992; Wolffe & Sacks, 1997). Lastly, in Part Three, parents of the adolescents who participated in Part Two were interviewed.



Chang and Shaller (2000) indicate that parental support and expectations strongly influence the activities of their children. In addition, Kef (1997) found that visually impaired adolescents identified their parents as an important source of social support and that they depended on their parents for support more than do sighted adolescents. Because of the parents' high level of influence as social supports, it is important to understand their perceptions of their adolescents' social participation and the meaning it holds for them. The meaning of social participation has not been adequately explored with parents of visually impaired adolescents. Questions including "What is the meaning to parents of their visually impaired adolescents' social participation?" and "How do parents' perceptions of social participation differ from the perceptions of adolescents?" were explored in Part Three of the study, using a phenomenological approach to gain insight into the parent participants' common experiences and perceptions.

### **Participants**

Inclusion criteria for teens with visually impairment participants were: 1) between 14 and 18 years old, 2) receiving services from a public school program for students who are visually impaired, 3) English-speaking, and 4) able to understand and respond to interview questions verbally. Exclusion criteria were: 1) presence of severe cognitive disability, 2) presence of severe communication disability or need for augmentative communication system. Inclusion for typically sighted teen participants were: 1) between 14 and 18 years old, 2) no documented visual impairment, 3) English-speaking, and 4) able to understand and respond to interview questions verbally. Inclusion criteria for

parents of teens with visual impairments were: 1) parent understands English. Exclusion criteria were: 1) lack of English fluency and 2) inability of participant to schedule 60 uninterrupted minutes for interview. Participants were invited and assigned non-randomly to either Group One (with visual impairment) or Group Two (with typical vision). Each member of each group completed the CAPE and PAC in interview format.

Teens with visual impairments were recruited through several area agencies serving families of visually impaired youth, the Department of Assistive and Rehabilitation Services (DARS) Division for Blind Services and American Foundation for the Blind Dallas Office. Recruitment material was also distributed through e-mail listservs for consumers and professionals, with consent of the sponsoring organizations. In addition, local low vision specialists and ophthalmologists, and support groups for parents and families were contacted. Recruitment efforts also occurred through word of mouth among the investigator's personal contacts and professional colleagues.

Teens with typical vision were matched by age and gender to Group One participants. Parents and youth were a convenience sample recruited through the investigator's professional and personal contacts. In addition, Group One participants and their parents were asked to recommend and provide information about the study to a sighted friend in the same school and grade who might be interested in participation to increase the possibilities of matching groups; however, this strategy did not result in participants.

## **Instruments**

**CAPE and PAC.** The Children's Assessment of Participation and Enjoyment (CAPE) and Preference for Activities of Children (PAC) are described as "companion measures" (King et al., 2004) and address the participation of children in a wide range of activities outside of school. The CAPE and PAC may be used with individuals between 6 and 21 years old and according to the authors, may be used with individuals with and without disabilities. The assessments can be self-administered, administered with help of a caregiver, or administered as an interview.

The CAPE consists of 55 different choices separated into five categories, or Activity Types: a) recreation, b) physical activity, c) social, d) skills-based, and e) self-improvement. Each activity choice is measured for five dimensions of participation: a) diversity of participation, b) intensity, c) with whom the activity is typically carried out, d) where/location, and e) enjoyment (Imms, 2008; King et al., 2004). Several different scales are used across the five dimensions. *Diversity* scores are the sum of the number of different activities in which a child participates, with a total of 55 activity options possible (King et al., 2004). This yields ratio data. *Intensity* scores are a report of the frequency of participation in social activities identified and use a scale from 1 (participated once in the last four months) to 7 (participated once every day during the last four months) (King et al., 2004). This scale is ordinal. *With Whom* scores indicate participation in a widening circle, from 'alone,' to 'with family,' 'with other relatives' (extended family such as grandparents or cousins), 'with friends,' and 'with others'

(“instructors, multiple types of people”), scored as 1, 2, 3, 4, and 5 respectively. The *Where* scale scores responses to “where do you do this most often?” from 1 to 6, with “at home,” the lowest (1) and “beyond your community” the highest (6). Other possible responses include “at a relative’s home,” “in your neighborhood,” “at school but not during classes,” and “in your community” (King et al., 2004). The *Enjoyment* scale is ordinal, scoring responses to “How much do you like or enjoy doing this activity?” on a scale of 1 (“not at all”) to 5 (“love it”). Table 1 shows the data type, as well as the scale range and parameters of each Dimension scale.

Table 1

*CAPE Dimensions, Scales, and Parameters*

<u>CAPE Dimension</u>	<u>Type of Data</u>	<u>Scale Range</u>	<u>Parameters</u>
<i>Diversity</i>	Ratio	0-55	“Have you done this activity in the past four months?” No=0, Yes=1
<i>Intensity</i>	Ordinal	1-7	"How often?" "1 time in the past4 months"=1 , " 1 time a day or more"=7
<i>With Whom</i>	Categorical	1-5	"With whom do you do this most often?" “Alone”=1, “With Others”=5

(continued)

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<i>Where</i>	Categorical	1-6	"Where do you do this most often?" "At home"=1, "Beyond your community"=6
<i>Enjoyment</i>	Ordinal	1-5	"How much do you like or enjoy doing this activity?" "Not at all"=1, "Love it"=5

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Three different scores can be used with the CAPE: Overall, Domain, and Activity Type. Overall scores provide broad view of participation and preference. Domain scores address level of participation in Formal (planned, structured activities) and Informal (spontaneous, unstructured activities). Activity Type scores address participation in the five categories of activities: Recreational, Physical, Social, Skill-based, and Self-improvement (King et al., 2004). The three types of scores can be used to assess an individual's participation or to compare groups.

Preferences for Activities of Children (PAC) addresses, as its name suggests, a child's preferences for the 55 activities identified in the CAPE. The PAC yields three scores: Overall, Informal, and Formal. The PAC Overall score provides broad information about the diversity of preferred activities (King et al., 2004). Informal and Formal scores indicate preferences for these categories of activities as opposed to actual participation in the activities. The authors of the CAPE and PAC point out that although

preference and participation influence each other, they are separate entities requiring separate examination (King et al., 2004).

Reliability, including internal consistency and test, re-test reliability, has been studied for both CAPE and PAC. Alpha values for CAPE internal consistency were .42 and .76 for domain type (formal and informal) and ranged from .30 to .62 for the five activity types. (King et al., 2004). Alpha values for PAC scores were between .76 and .84 for domain type and between .67 and .77 for the five activity types (King et al., 2004). Test re-test reliability, reported as intra-class correlation coefficients, varied across domains and dimensions for CAPE, from .64 (formal domain, enjoyment dimension) to .86 (formal domain, intensity dimension) (King et al., 2004). Reliability coefficients for Activity Type also varied across dimension and type, from .67 to .77 for Diversity, .72 to .81 for Intensity, and .12 to .73 for Enjoyment (King et al., 2004).

**Interview.** A semi-structured interview guide with probes was developed based on categories addressed in the Social Network Pilot project (Wolffe & Sacks, 1997): daily living activities, school activities, recreational activities, personal management activities (shopping, banking, and medical appointments), travel activities (functional mobility), and work activities. These areas are consistent with the American Occupational Therapy Association's accepted definition of social participation (AOTA, 2014) as well as current International Classification of Functioning disability and Health (ICF) categories-(World Health Organization [WHO], 2002).

The interview schedule for the adolescents with visual impairments was based on a three interview method described by Seidman (1991), in which the first interview establishes context, the second interview focuses on details of the experience, and the third focuses on the participants' understanding of the experience. Parent interviews followed this in a modified format, using the first interview to both establish context and obtain detailed information and the second interview to reflect on meaning. This was considered appropriate as the parent was present during explanation the first part of the study and so had an initial introduction to the context.

### **Procedures**

After IRB approval was obtained, recruitment fliers and requests for distribution were sent to area agencies serving adolescents with visual impairments, parent and professional associations, and optometrists and ophthalmologists. The investigator also obtained permission to personally present information about the study to parents at various DARS-sponsored and other events, including goalball practices. When a parent expressed interest in participation, the investigator arranged a meeting in a location convenient to the family or via telephone to fully explain the study and obtain consent for participation from both the parent and adolescent. If all contact took place via telephone, consent forms were sent to potential participants via mail or in electronic format. After consent and assent were obtained, adolescents were administered the CAPE and PAC. These assessments were administered to all participants in structured interview format. Data obtained were analyzed for patterns of engagement in activity Domain (formal and

informal), Activity Type (recreation, physical activity, social, skills-based, and self-improvement), and Dimension (diversity of activities, intensity of engagement, engagement with others, locations of participation, and enjoyment) (King et al., 2004). Data collection took place either face-to-face or over the phone, depending on participant preference and location. All participants who lived more than 25 miles from the investigator's home were interviewed by phone. A total of four meetings were possible for adolescent participants with visual impairments; one meeting for typically sighted adolescents; and three possible meetings for parent participants. The time needed for completing the CAPE and PAC was between 30 and 60 minutes. If the parent and adolescent were participating in interviews, attempts to schedule a second appointment were made at the end of the visit.

Parental consent and adolescent assent forms for interviews were obtained by the investigator when the individuals agreed to participate. The interview schedule comprised one interview with non-visually impaired adolescent participants, three interviews (one structured and two semi-structured) with three of visually impaired adolescent participants, two interviews with two visually impaired participants (one structured and one semi-structured) and two semi-structured interviews with two parents, and one with one parent. In addition, member checking via telephone or face-to-face meeting took place with all adolescent participants with visual impairments and with three parents during data analysis.



Each adolescent participant was to have completed two semi-structured interview sessions with the investigator; however, second interviews did not always take place. Reasons for deferral of the second interview included participant illness, death in the family, or schedule conflict and fatigue. Participants were given the option of completing the first interview on completion of Part One of this research. If the participant chose to be interviewed in a separate session, an appointment was made at that time. Attempts to make an appointment for the second interview were made on completion of the first. Interviews were arranged at a time and location convenient to the family of the participant. Interview locations were quiet and offered privacy, such as a room in the family home, a conference room at the university campus, or other site. Interviews were audio recorded on the investigator's digital recorder. The investigator also compiled field notes during the interviews and immediately after each interview. After initial analysis and organization of data into broad themes, second interviews were arranged with three participants. Parent interviews took place either via phone or in-person. Interview locations were quiet and offered privacy, such as a room in the family home, a conference room at the university campus, or other site. All interviews were recorded on the investigator's digital recorder. Audio recordings were transferred to a flash drive file and were manually transcribed by the investigator. All teens with visual impairments and parent participants took part in member checks.

## **Data Analysis**

Nonparametric testing was most appropriate due to the small number of participants and due to ordinal scales used within the CAPE and PAC. Assessment data were analyzed using nonparametric testing (Mann-Whitney U) for between group differences (visually impaired and typically sighted) in CAPE. Overall scores for each dimension addressed (*Diversity, Intensity, With Whom, Where, Enjoyment*), Activity Type (*Recreational, Physical, Social, Skill-based, Self-improvement*) and Domain (*Informal, Formal*). Between group differences were also investigated using Mann-Whitney U test for PAC Overall scores and for PAC Domain scores. In addition, individual scores for the group with visual impairments were analyzed in case-by-case format in relation to the individual participant's interview data.

Analysis of interview data utilized a qualitative descriptive approach (Lambert & Lambert, 2012) to identify and describe the experiences of the participants. Themes were identified in several stages. First broad theme categories of individual interview data were formed through repeated reading of each transcript sentence and labeling (coding) emergent meaning. Second interviews were treated in the same way. Relations among the initial codes were identified. Main emergent themes that encompassed the essence of each participant's interview were identified. Broad themes were member checked.

Parent-adolescent dyads were then analyzed for contrasts and commonalities. The investigator's participant observation notes were incorporated into this part of the analysis as well to provide further context and immediacy of the data. Emergent themes

of the dyads were identified by first comparing the individual's (adolescent or parent) themes to the dyad's partner, then coding for common or contrasting experiences and perceptions. Case-by-case analyses and summaries were then developed for dyads and for the two non-dyad adolescent participants.

Trustworthiness measures included member-checking of summaries of interview data and emergent themes with all five teen interview participants via telephone or additional face-to-face meeting, and with the three parent participants via telephone. In addition, triangulation among multiple data sources was used. Individuals' interview data were compared to their CAPE and PAC results and to themes common to the interviews as a whole. Data from individual parents were compared and contrasted against each other and as stated above, compared to common themes. In addition, an audit trail was maintained, including audio files of interviews, transcripts of interviews, personal and participant observation notes, and synthesis notes.

## CHAPTER IV

### RESULTS

Five teens with visual impairment aged 14 to 16, currently receiving services through public school programs for students who are visually impaired, participated in the study. Five typically sighted (no documented visual impairment) teens were recruited for age match (age 14 through 16). Additionally, three individual parents of visually impaired teens participated in the interviews.

The results of the CAPE and PAC comparing typically sighted adolescents with adolescents with visual impairment are presented first. Case study analyses of the adolescents with visual impairment and their parents are presented following the CAPE and PAC results.

#### **CAPE and PAC Comparative Analysis of Adolescents with and without Visual Impairment**

Ten adolescents completed the CAPE and PAC. Five were visually impaired and five were typically sighted. They were matched by age and gender. Table 2 presents the participants' demographic information regarding visual condition/etiology, functional vision status, and match.

Table 2  
*CAPE and PAC Demographics*

Visually Impaired	Visual Condition/Etiology	Vision Status	Typically Sighted Match	Age	Gender
Guillermo	Retinoschisis	No vision in one eye; field loss in other eye	John	15	M
Lisa	Leber's Congenital Amaurosis	Blind	Molly	16	F
Seth	Leber's Congenital Amaurosis	Blind	Irwin	14	M
Esther	Retinopathy of Prematurity	20/100 distance acuity; reads standard print	Lucy	15	F
<u>Hal</u>	<u>Cancer</u>	<u>Blind</u>	<u>Lou</u>	<u>16</u>	<u>M</u>

The CAPE and PAC were administered by the investigator as an interview. Responses were written by the investigator onto the record forms. CAPE Group Scores (Visually Impaired and Typically Sighted) were compared for Overall, Domain and Activity Type. PAC scores were compared between groups for Domain preferences. Individual scores for the adolescents with visual impairments will be discussed in detailed case studies.

### **CAPE Scores: Group Comparisons**

*Overall scores.* No significant differences were found in the Overall scores between groups in the dimensions of *Diversity*, *Intensity*, *With Whom*, *Where*, or *Enjoyment* scores. Comparison of *With Whom* scores between groups suggested a possibility for further investigation ( $\alpha = .05$ ,  $p = .095$ ,  $U = 4.00$ ,  $z = -1.781$ ). Although differences did not achieve statistical significance, the scores for the group of adolescents with visual impairment were slightly higher than the group of participants with typical vision. These scores suggest that this participant group of adolescents with visual impairments participates with a wider range of people than their sighted peers.

*Domain scores.* No significant difference between groups was found for Domain scores at the Formal or Informal level. Although not statistically significant, it was noted that the group with visual impairments generally reported more diversity of formal activities than the group with typical vision. Participants in the group with visual impairments reported more involvement in formal than informal activities.

Figure 1 shows between group results for the CAPE Formal Domain scores. It can be seen that higher *Diversity* scores in the group with visual impairments may be attributed to two of the participants (Lisa and Esther) while other participant *Diversity* scores are quite similar between groups. One participant in the group with visual impairments (Esther) reported a higher intensity of participation in Formal activities than participants in either group. Reported *With Whom* scores are slightly higher among the

group with visual impairment than the group with typical vision. *Enjoyment* ranges are similar between groups.

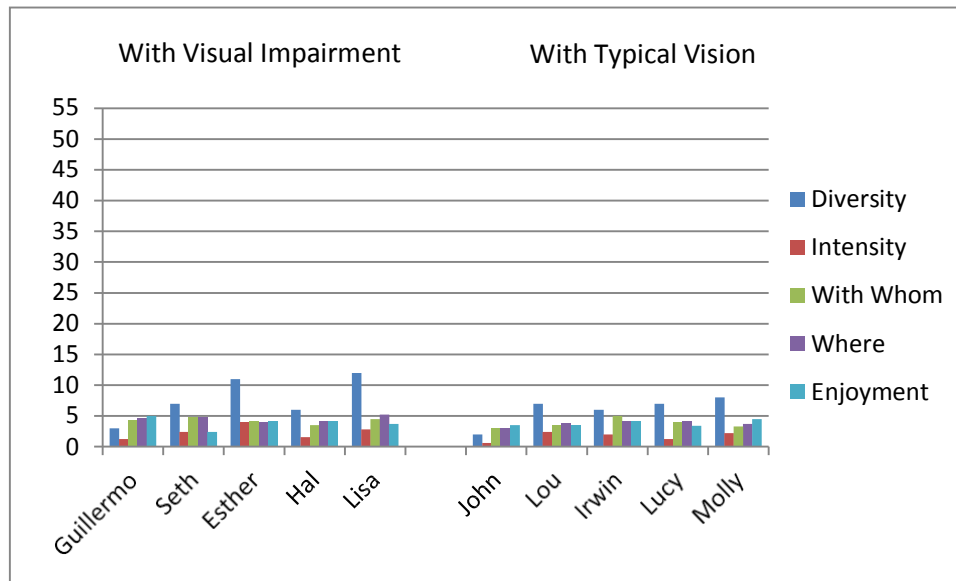


Figure 1. CAPE formal Domain scores for participants with visual impairments compared to participants with typical vision.

As can be seen in Figure 2, the highest *Diversity* of Informal activities is reported by a participant with typical vision (Molly) and the lowest by a participant with visual impairment (Guillermo). Guillermo also reported the lowest *With Whom* and *Where* scores of all participants. Other scores are similar across groups and participants.

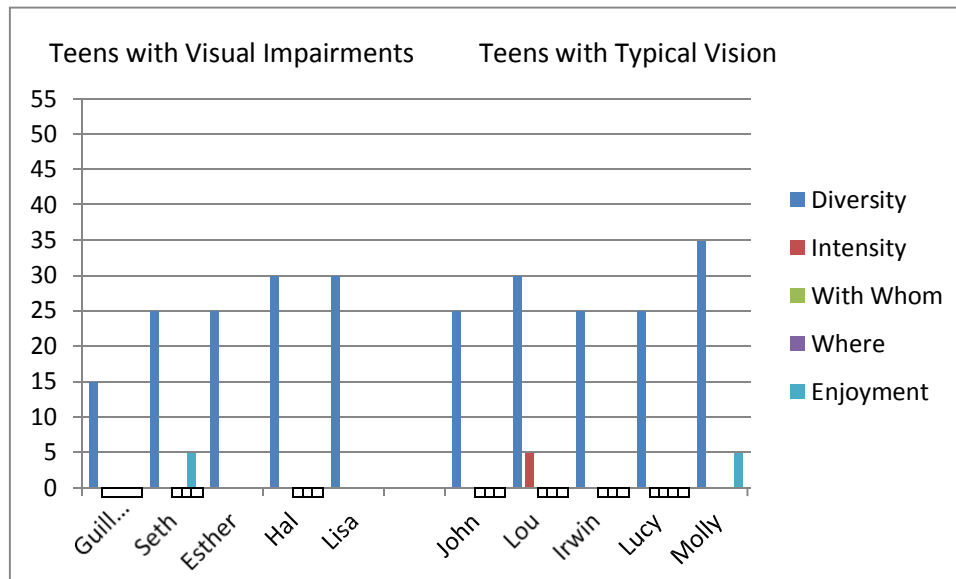


Figure 2. CAPE informal Domain scores for participants with visual impairments.

**Activity type scores.** No significant difference was found between group scores for Activity Type (*Recreational, Physical, Social, Skill-based, Self-improvement*) in the dimensions of *Diversity, Intensity, With Whom, Where, and Enjoyment*. Comparison of group scores for Activity Type-*Recreational*, in the *Where* dimension ( $\alpha = .05$ ,  $U = 4.5$ ,  $p$  value =  $.095$ ,  $z = -1.67$ ), suggested a possibility for further investigation. The group with typical vision scored slightly higher than the group with visual impairment in this area. Although the group with visual impairment participated with a wider range of people as noted in the Overall level scores, this group tended to do so within their own communities.

Figure 3 shows CAPE Activity Type-Recreation scores. *Diversity* scores are generally higher among the participants with typical vision. *Intensity* levels are fairly similar between groups although one participant with visual impairment (Lisa) reported



markedly lower *Intensity* than all other participants, and one participant with typical vision (Lou) reported a markedly higher intensity level. *Enjoyment* levels are similar across groups, with both the highest and lowest scores reported within the group of participants with visual impairment.

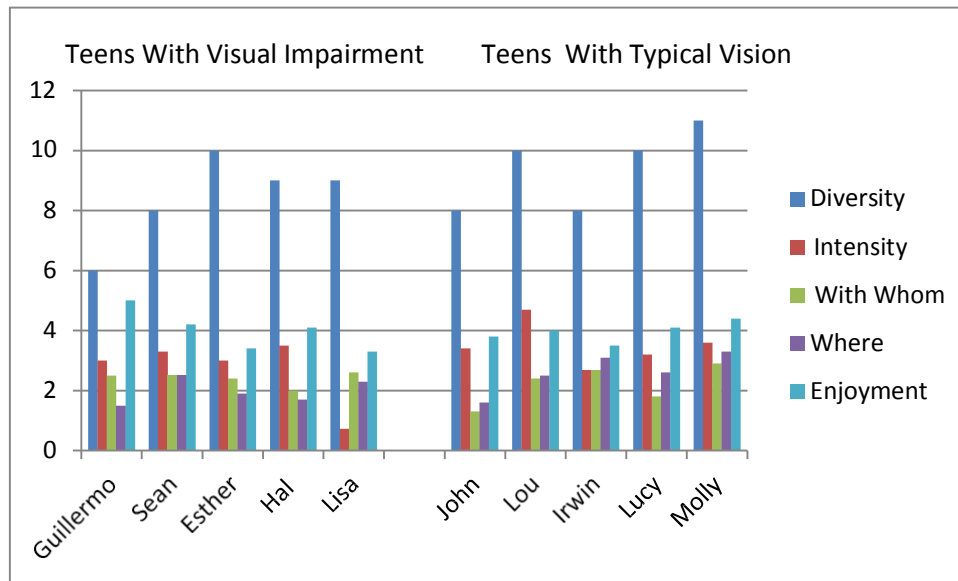


Figure 3. CAPE Activity Type-Recreation scores for participants with visual impairments compared to participants with typical vision.

**PAC Scores.**

**Domain and overall scores.** No significant difference was found between groups in scores for Formal or Informal Domain. Group scores are shown in Figure 4. Participants with visual impairment tended to indicate slightly less broad activity preferences than participants with typical vision, indicated by Overall scores. As can be seen in Figure 4, three of the participants with visual impairment and three of the

participants with typical vision reported preferences for Formal activities. One of the participants with visual impairment (Guillermo) and one of the participants with typical vision (John) indicated a preference for Informal activities.

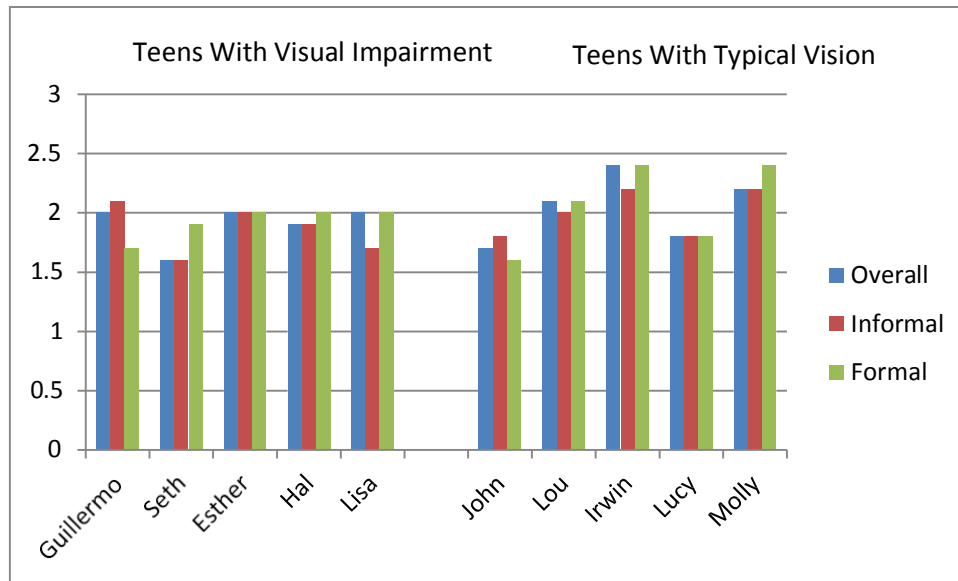


Figure 4. Group PAC scores of participants with visual impairments and participants with typical vision.

### Case-By-Case Analyses

Each participant's unique narrative is introduced in this section, with a case-by-case analysis including information about each teen's visual condition in functional terms, data from CAPE and PAC, description of interview data in relation to CAPE and PAC scores, and summary of interview responses. To allow the participants to speak in their own voices, significant amounts of the transcribed interviews are included, as possible.

The school-based, school-aged visual impairment community (the professionals refer to themselves as “vision professionals”), including students and professionals, is small and tends to interact frequently through local, regional, and statewide events. It is highly likely that some of the participants could be identified through the details they shared. Therefore, city and school district names are not used (with the exception of Texas School for the Blind and Visually Impaired and generic Education Service Centers) nor are names of school personnel or doctors. Participants were assigned pseudonyms, which are used throughout.

**Esther and Judy.** Esther is a 14 year old girl with a diagnosis of high myopia secondary to retinopathy of prematurity. Her distance visual acuity per her mother is about 20/100 using both eyes with best correction. She sees well enough at near ranges to read standard print at about four or five inches. Esther is a sophomore in high school and attends public school academic general education classes. She receives special education services from a certified teacher of visually impaired children (vision teacher) and a certified Orientation and Mobility Specialist (COMS). She lives with her parents Judy and Barry in a suburb of a large city. Esther completed the Children’s Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC) as well as an interview on the same day. Her mother was present in the room throughout. Results of the CAPE and PAC are presented below.

***Esther’s CAPE and PAC findings.*** Table 3 presents Esther’s CAPE and PAC scores in numeric format.

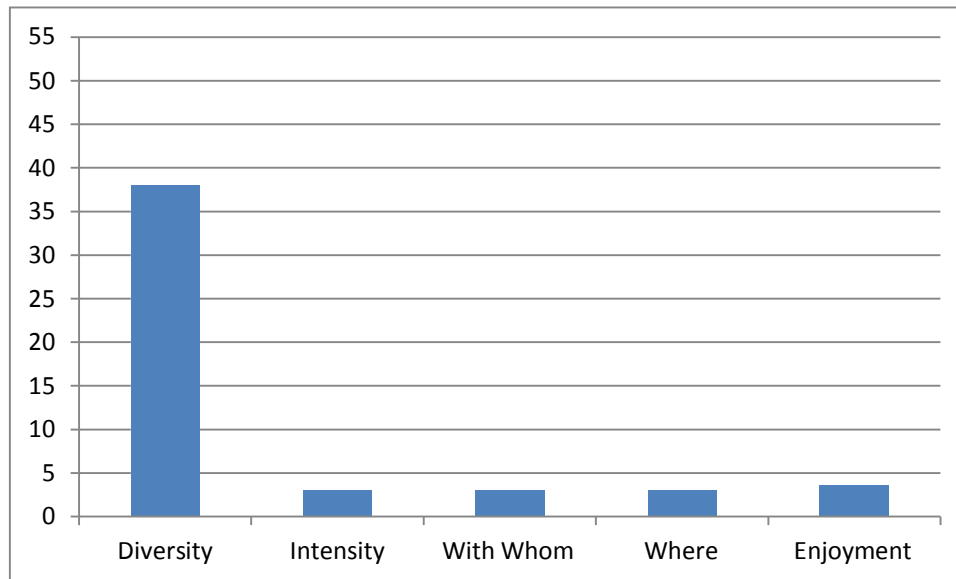
Table 3

*Esther's CAPE and PAC Data*

	CAPE	Diversity	Intensity	With Whom	Where	Enjoyment
Overall		38	3.1	3.1	3.1	3.6
Activity Type						
recreation		10	3	2.4	1.9	3.4
physical		3	1.2	4.3	4.6	4
social		7	3.1	3.4	3.2	3.7
skill-based		7	3.1	3.4	3.2	3.7
self-improvement		10	4.6	2	3	2.3
Domain						
informal		27	2.8	2.7	2.8	3.4
formal		1	4	4.2	4	4.2
PAC		Overall	Informal	Formal		
Overall		2	2	2		

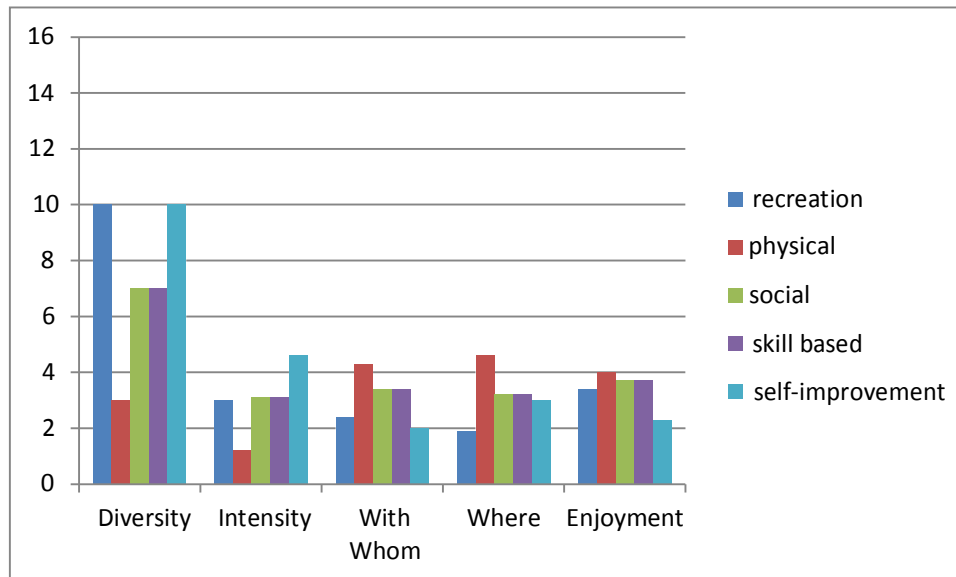
Figures 5, 6, 7, and 8 present the same information graphically. It is clear

in Figure 5 and Table 1 that Esther has a moderate diversity of activities (38 of 55 possible) and moderate intensity of participation (3.1 on a scale of 5).



*Figure 5. Esther's CAPE Overall score.*

As can be seen in Figure 6, the primary activity categories in which Esther participates are recreation and self-improvement, followed by social and skill-based activities. Physical activities were rated the lowest in *Diversity* and *Intensity*, but highest in *With Whom*, *Where*, and *Enjoyment*.



*Figure 6. Esther's CAPE Activity Type scores.*

In Figure 7, it can be clearly seen that Esther participates in a greater variety of Informal than Formal activities. However, she participates in formal activities more frequently than she does informal. Her formal activities take place with a wider range of people, in places farther from home, and with more enjoyment than do her formal activities. It makes sense that this supports information shown in Figure 6 (Activity Type). Esther's physical activities tend to be team sports such as karate and goalball, both formal activities.

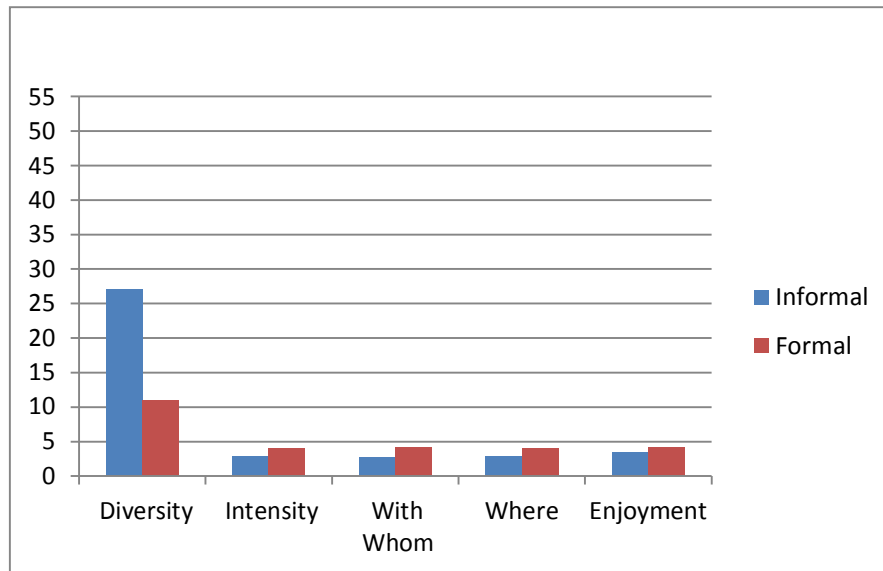


Figure 7. Esther's CAPE domain scores.

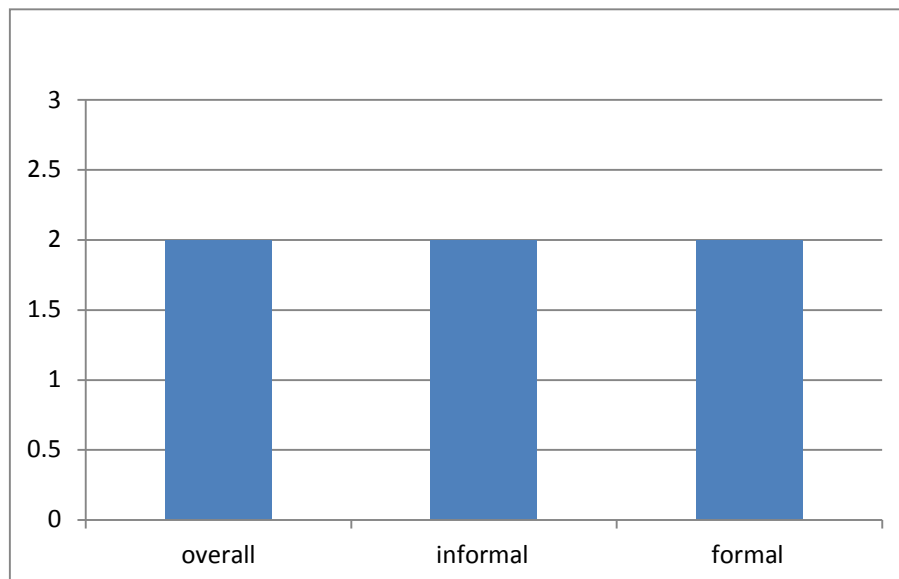


Figure 8. Esther's PAC scores.

As can be seen in Figure 8 (PAC scores), Esther does not express a preference for formal over informal activities.

An apparent conflict was noted in Esther's test scores. The test data show that one of the primary activity categories in which she participates is self-improvement, but they also indicate that Esther's lowest level of enjoyment is with self-improvement activities. She states in her interview that she enjoys trying out new things. Additionally, when asked during her member checking visit how she would explain it (most frequent participation in activities are in the self-improvement category but so is lowest enjoyment level), Esther responded similarly. From my notes of the visit: "I try new things and they may be difficult so at the time I'm doing them, I'm not enjoying that much. But I really enjoy learning the new things and things I have to work at."

Esther's interview data support data obtained through the CAPE. Of note, Esther's CAPE scores show that she participates in formal activities more frequently and with more enjoyment than she does informal activities. In her interview, Esther described a mix of activities with friends, ranging from just hanging out to participating in the karate demo team and goalball. She spoke about both her team-based activities and her unstructured time with friends.

With my friends I enjoy, just, like, hanging out and talking with them, sometimes in person, sometimes over text. I enjoy playing video games with them. And some of my friends at school, we're all in karate together, so I enjoy doing the demo team with them.

***Thematic analysis.*** Four themes stood out in the data from Esther and her mother's interviews. These are: "disability or not/requiring protection or not," "self-



direction,” “same just different family and self,” and “challenges of parenting.”

“Disability or not/requiring protection or not” includes perceptions expressed by Esther and her mother regarding her visual impairment, its effect on Esther’s life, and supports and barriers to her social participation. “Self-direction” deals with Esther’s interests, approach to social barriers, and decision making. “Same, just different family and self,” involves perceptions of family and individual activities in comparison with typically sighted peers and their families. “Challenges of parenting” includes perceptions expressed by Esther’s mother regarding her experiences at various milestones in Esther’s life.

*Disability or not/requiring protection or not.* Esther’s mother expresses in her interview that Esther tends to prefer solitary activities and is self-conscious or shy in social situations. She attributes this in part to typical adolescent behavior and in part to Esther’s visual impairment.

She is somewhat shy in big gatherings and I wonder sometimes if that’s the nature of teenagers today...When we’re in a social situation with new people, I think she gets a little shy because she can’t necessarily see them or identify somebody from far away, even if it’s someone she knows - or she’ll sometimes think it’s someone and it’s not and I think that makes her a little uncomfortable.

Judy also tends to attribute negative events to Esther’s visual impairment, until countered by Esther. For instance, discussing incidents of bullying, Esther’s mother wonders if bullying occurs because Esther stands out when she uses her cane. Esther

doesn't feel the bullying incidents were related to her vision. Judy then concedes that there were others bullied as well. "Yes she's had a couple of things but the people were jerks to other people. They weren't targeting her; they were targeting other girls as well. So in that sense..." She identifies that the environments in which school dances are held present a barrier to Esther's social participation, "she doesn't want to go to any of the dances. And I don't know if that's because of her vision or because...it's dark, well, and the first one she went to she slipped and fell and bumped her head." Esther, however, says about the same event, "So OK...so it was really, really dark and...I spilled some water and, of course, it was dark so you can't see anything...And that could have happened to anybody." Esther presents that the negative events were not specifically vision-related and were minor situations that anyone, regardless of his or her vision might experience.

Judy identified additional social barriers related to Esther's vision and access to information. A social participation barrier associated directly with school and involving access to information was lack of appropriate accommodation. "She's not getting the large print like she should and so we're kind of working on that...to take away the barrier of ... the print..." Information in a critical class is not provided in an accessible manner and this diminishes Esther's ability to participate at the same level as her peers. Esther, in her member check visit, described missing assignments due to not seeing the information written on the board. However, she volunteers that she could have walked closer to the board before the end of class to read it, but chose not to as she didn't want to stand out.

Esther sees the barrier as her responsibility to address. There is a tension between the views Esther and her mother present of her visual impairment. Judy views the impairment as a disability from which Esther needs protection, while Esther views it as just a part of life.

*Self-direction.* Esther and Judy both discuss aspects of Esther's self-direction. Judy says, "This is a child who will say, 'I want to be alone, I want to go write.' So she can be alone and be very content doing her favorite things." She also describes Esther exploring her options for the future, "I'm always proud or excited when she says 'Do you think this is a job I could do?' after something comes up."

Esther states that she likes trying new things. Her approach to pressure from others is illustrated with the following story related during member check: A peer accused Esther faking her visual impairment because she used a long white cane for safety on unfamiliar stairs but does not typically use it in familiar areas. Esther said she often feels self-conscious now when she uses her cane. However she also said she felt she did not feel the need to educate or explain to others who did not understand or accept her "I'm not anyone's 'Blindness 101' class."

Esther wants to be a writer. She is working to support that goal with her school program by taking advanced English classes and planning an English or creative writing major for later. She downplays, but does not ignore, barriers that she may encounter in the future because of her visual impairment.

...in terms of my vision, I think it's going to hurt a little bit because I know that people who have impairments have a little more difficulty getting jobs and such. But I'm not really worried about that. It's just something that's there, and I know about it, and I'm ready to deal with it but I don't think about it too much... 'But ...I don't think it's going to be that big of a problem.

*Same just different family and self.* Esther and Judy report that Esther has a mix of typically sighted and visually impaired friends. Esther sees her typically sighted friends more frequently than those who have visual impairments. Esther tends to separate her activities between the two groups.

...my closest friends are the friends that I go to school with or hang out with around my neighborhood, and most of them are able-bodied [typically sighted]...But outside of that circle, I have a goalball team and I'm really close friends with those people and most of them have visual impairments and or are blind.

Judy agrees. Although Esther's friends and activities are not chosen on the basis of her vision, her mother still notices that Esther seems a bit more comfortable when participating in an activity she has in common with others such as karate with typically sighted teens and especially in goalball with other visually impaired teens.

When I've seen her in the karate room, with the friends, she's very happy and comfortable there. And then when she's at goalball, I do feel like they're definitely experiencing a common bond. That they share something that only

they can understand and, you know, that regularly sighted people don't quite get... And they have an interesting discussion like, "What's your vision?"...and it's just not a question you would have with your other friends.

Esther and Judy see their family activities as no different from activities of other families. Judy feels that Esther's activities and behavior at home are fairly typical of a child her age. She sees her as occasionally not following through with responsibilities and sometimes being idle.

Esther describes her responsibilities in her home as perhaps less than other, typically sighted peers, but basically the same as theirs. She hasn't discussed her chores with her friends for comparison.

It's really not all that much, I'm just making a deal out of it. I have to feed the dog and the cat when I get home, and I have to keep my room in order (mother laughs), TRY to, it doesn't always work. I have to hang up my clothes (Says to Judy, smiling, "Hey, don't laugh at me!"). I usually set the dinner table and sometimes I help my dad with cooking. Sometimes I help clean up the kitchen after dinner, like wash dishes and stuff, and then there's walking the dog...and cat...

Volunteering in the community and activities related to her religious group have a large role in Esther's social life. She works in a community garden that supplies a local food bank. Although she started this in part as a religious obligation (she did it as a community service requirement for her bat mitzvah), she continued her participation in it

by joining a related (at the synagogue) gardening class after she fulfilled her requirement. Esther volunteers for other causes as well. She participates in Relay for Life (American Cancer Society) and indicates she joined this due to knowing a child with cancer and wanting to help.

Esther relies on her parents as her primary mode of transportation to her activities. She and Judy state her peers also rely on their parents for transportation. In her member check visit, Esther reiterated that she relies on parents for transportation. By the date of the member checking visit, Esther and her friends were old enough to drive, but she said she did not like to drive with her friends as she does not trust their abilities yet. Esther also expressed jealousy at her friends' freedom and ability to drive, however. "They [typically sighted peers] can just jump in their cars at 3 am if they want to and go wherever; they might get into trouble, but they could do it."

Judy states that she and Esther's father value family social involvement. They have found activities they feel are parallel to those in which families with typically sighted children engage.

For instance, goalball is for us what soccer is for other families. Or baseball, they have this...team, that they do the same thing...so goalball for us is nice to be able to rally around something that she is doing and we're involved with it because she's helping coach...

Because the family highly values social time together, the parents find activities in which they can all be involved. Just as Judy pointed out that Esther bonded with

friends who were visually impaired and on the goalball team because they had experiences in common, she sees common experiences as important in building family connections. As other families may share loyalty to a baseball team and support their children's position on it, this family supports Esther's individual involvement on the goalball team and makes it a family event. Judy feels this family-based social emphasis helps in Esther's overall social participation.

*Challenges of parenting.* Judy identifies supports to Esther's social participation now and in the future. Supports include Esther's VI teacher and O&M instructor, the Department of Assistive and Rehabilitative Services Division for Blind Services (DARS) and a regional Education Service Center. She states that she and her husband enjoy good relationships with Esther's VI teacher and O&M instructor and other professionals involved with Esther's activities. Judy views Esther's current activities as laying the basis for the future.

...She reads computing books. On the internet, she's often very tuned in to what's going on in the world, and on TV she'll watch the news sometimes with me. But she really knows what's going on in the world which is pretty cool for a 14 year old. So I think she's got interests in so many things that that will help her in her future.

Asked what she would like to see Esther do in her adult life, she identifies college attendance, living independently, and supporting herself financially. She encourages Esther in career exploration. Although she acknowledges that Esther's vision may change

or may challenge her goals, she expresses certainty that Esther will be able to manage it.

She says,

...I hope she will... go to college and... live in a situation where she's not living with her parents but with a friend or alone or somehow independent of us, and I think she'll be able to do that. I'd like to see her have a dog [dog guide]... I think that her passion for writing is hopefully a lifelong passion that she'll want to pursue as a career. Her vision has always been stable so we're really not expecting that to change, but I think if it changed she's had enough exposure to all, you know, all degrees of visual impairment and I think she would handle it. I mean she would do what she needed to do to make it work for her...So I think, you know, she'll do OK. I'm looking; I mean it's scary for any parent.

***Esther and Judy summary.*** Overall, Esther presents herself as a typical teen. She insists that many of the difficulties she has encountered (bullying, slipping and falling) are not in any way related to her visual condition. Esther did not bring up her negative experiences during her interview; her mother did during her own and Esther joined in.

Judy seems to struggle a bit with her own perception of how visual impairment affects her daughter, or visual impairment as a disability, in contrast to her daughter's presentation of visual impairment as simply a physical trait. She does however, seem to try to encourage Esther's sense of strength and normality. Twice during her interview, she changed her focus of the cause of negative events: she changed to agree with her daughter regarding bullying not targeting Esther because of her impairment but because



she is just one of several being bullied and she changed to agree with Esther that slipping at a school dance was unrelated to her vision.

Judy, like Esther, presents Esther generally as a typical teen. She states that she and her husband try to find activities they can do as a family, like any other family.

Judy identifies Esther's school-based vision team as strong support and is hesitant to report any barriers. The primary barrier she has encountered at school is lack of accommodation by a general education teacher. Overall, Judy views her daughter as quite capable and several times during her interview says she thinks the things Esther does are 'cool.' Judy views social participation as key to her daughter's future success and feels that she is progressing in this area.

**Guillermo and Sam.** Guillermo is a 15 year old boy with retinoschisis and cataracts. He is able to read enlarged print on a video magnifier. He has no vision in his left eye. Guillermo attends public school and receives services from a certified vision teacher and has received Orientation and Mobility (O&M) in the past but does not now. He also has received some services from DARS but he tends not to attend events they sponsor as he is more involved with extracurricular school sports. He lives with his father, Sam, in a large city. Sam is the primary parent in Guillermo's life (neither mentioned a mother). Sam's interviews took place separately from Guillermo's, via telephone. Sam's second interview took place approximately 11 months after his initial interview. Guillermo completed the CAPE and PAC one day and the first interview the next, via telephone. His second interview took place approximately nine months later.

*Guillermo's CAPE and PAC findings.* Table 4 provides Guillermo's CAPE and PAC information in numeric form. In Table 4 and Figure 9, it can be seen that Guillermo reports an overall low level of activity diversity (18 of 55 possible) and intensity. His level of enjoyment however is relatively high.

Table 4

*Guillermo's CAPE and PAC Data*

	Diversity	Intensity	With Whom	Where	Enjoyment
Overall	18	1.9	3.3	3.1	4.9
Activity Type					
recreation	6	3	2.5	1.5	5
physical	4	1.9	4	4.7	5
social	4	2	4	3.7	4.7
skill-based	1	0.7	4	4	5
self-improvement	3	1.8	3.3	3.3	5
Domain					
informal	5	2.2	0.87	0.83	1.3
formal	3	1.2	4.3	4.6	5
PAC	Overall	Informal	Formal		
	2	2.1	1.7		

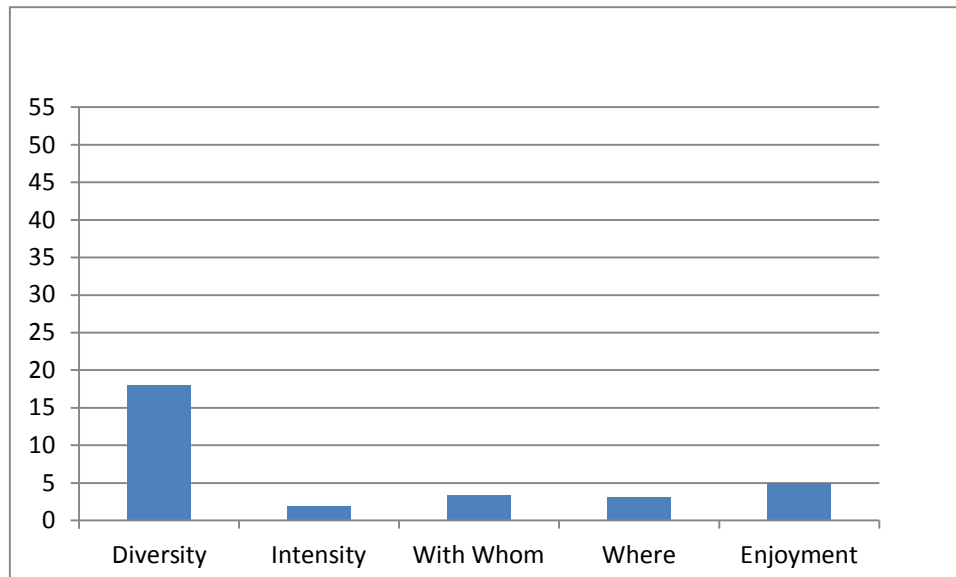


Figure 9. Guillermo's CAPE Overall scores.

As shown in Figure 10, Guillermo reports most diversity and intensity of recreation activities, followed by physical and social, with skill-based activities rated lowest in diversity and intensity. Guillermo's scores indicate he participates with the widest range of people in physical, social, and skill-based activities. His recreation activities rated lowest in the *Where* category, indicating these are carried out closest to his home area of all his activities. His enjoyment levels are fairly consistent across all activity types, with social rated slightly lower than the others.

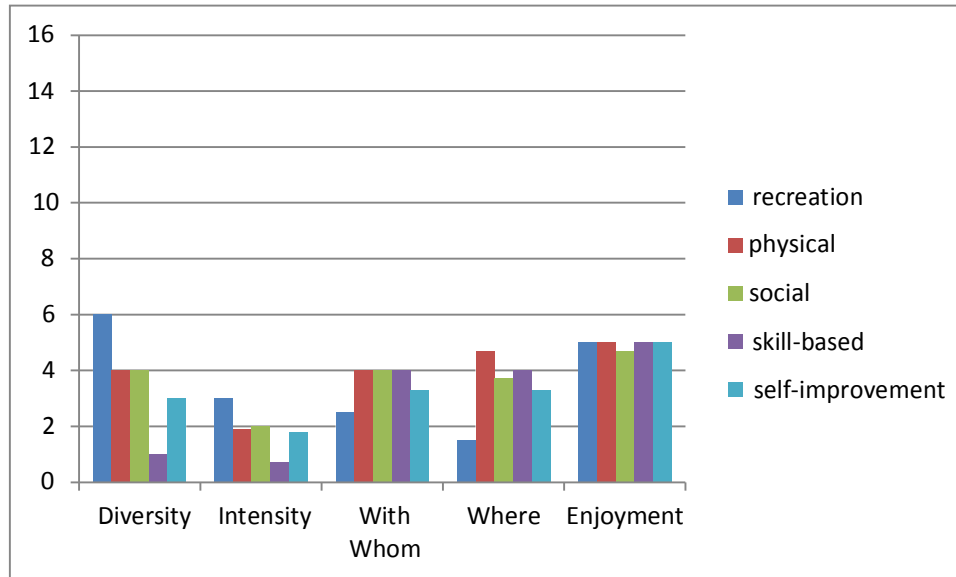


Figure 10. Guillermo's CAPE Activity Type scores.

Figure 11 shows that Guillermo reports participation in a much wider diversity of informal than formal activities and at a slightly higher intensity (frequency). However, Guillermo reports much greater enjoyment of formal activities than informal.

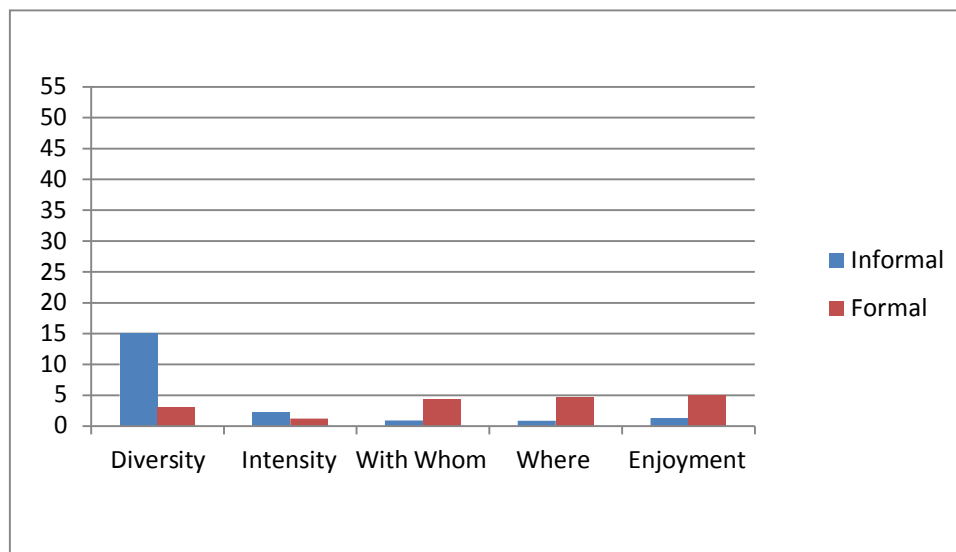
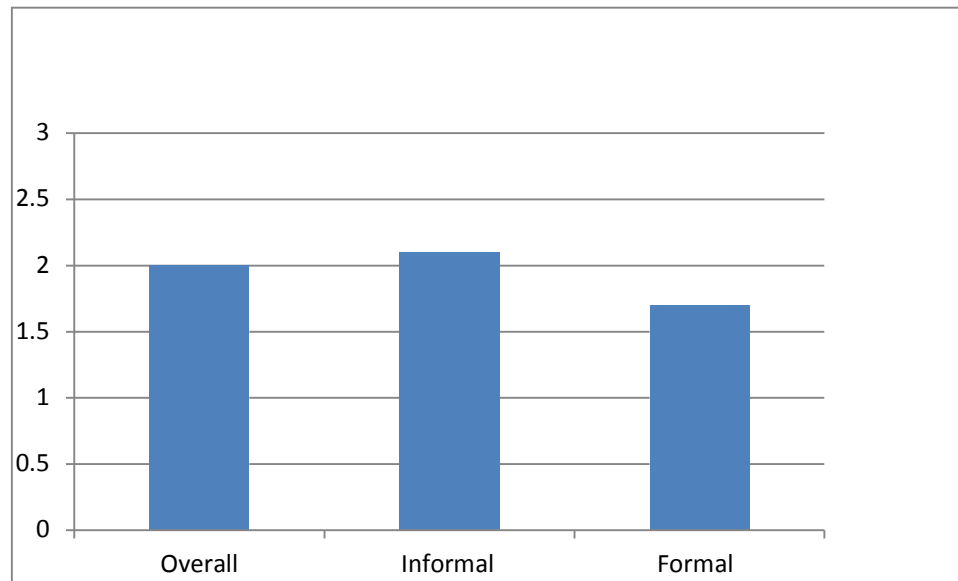


Figure 11. Guillermo's CAPE Domain scores.

As can be seen in Figure 12, Guillermo's PAC scores are inconsistent with his CAPE Domain scores. Guillermo reports a slightly higher level of preference for informal than formal activities.



*Figure 12.* Guillermo's PAC scores.

The discrepancy in Guillermo's CAPE Domain and PAC scores reported above may be accounted for by Guillermo's and his father's view of team sports. The importance placed on team sports by this family may account for the CAPE domain score indication of greater enjoyment of formal than informal activities. Even if he doesn't enjoy the actual activity as much as informal activities, he enjoys the benefits that come with it and he is expected to want to participate in them. However, while Guillermo feels that organized sports are important, in actuality he may wish to do more spontaneous activities, as indicated by his PAC scores and interview. Although Guillermo may not participate in organized sports as much as he does informal bike riding or working out in

a gym, during their interviews he and his father placed a great deal of importance on team activities. Guillermo views team sports as important to making and keeping friends, as well as a way to be like his peers, evidenced by his statement:

I play rugby so a lot of my friends that I've made over the past year definitely have been my team. And I also ride BMX bikes and so whenever I go somewhere with one of my friends I meet someone new and riding a bike is that quality that we share so getting something to share like that.

Sam, addressing team sports said,

...with him playing rugby, it's not about the team...It's about him developing skills, as a team with his teammates. Developing confidence, developing, uh, a type of camaraderie amongst the guys, you know?

Sam clearly sees benefit in his son participating in organized sports. He views it as an opportunity for promoting his son's maturation, confidence, being a part of something more than himself, and belonging.

***Thematic analysis.*** Four themes emerged from Guillermo's and Sam's interview data. These include: "Just being able to go wherever I want," "the importance of sports," "protection and freedom to grow," and "like but not like others." "Just being able to go wherever I want" includes Guillermo's and his father's perceptions of control of Guillermo's mobility and freedom compared to his peers. "The importance of sports" developed from Guillermo's and his father's statements about the role teams and physical activities play in Guillermo's social participation. "Protection and freedom to grow"

includes Sam's perceptions of the tensions he encounters as a parent. "Like but not like others" is a theme that emerged as Guillermo and Sam talked about Guillermo's social experiences in relation to typically sighted peers.

*Just being able to go wherever I want.* Freedom of movement is important to Guillermo, evidenced by the quote below. He knows he will not be able to drive because of his vision impairment and biking gives him a sense of independence and spontaneity.

I like being able to bike around, whether it's a road bike, a mountain bike or a BMX... Just being able to go wherever I wanted to. I mean, obviously, I'm not going to be able to keep a car, I mean ... I have traveled a lot on a bike. But just being able to be out, I guess, and like travel somewhere new, it's really, I like the idea.

He describes other modes of functional mobility. He relies on his father or a team mate to get to his sports practice. Walking is an option he uses if an event or destination is close. Sam states that right now he is the main provider of Guillermo's transportation to events in the community. His city does not have very good public transportation and Guillermo's peers all rely on their parents for rides. Guillermo has had O&M services through school in the past; however, his father states that he is concerned about Guillermo travelling alone in the community.

...every time he steps out that front door and goes for a bike ride, yeah, it really bothers me, you know? Just crossing the street where there's a light you know?

Hey, you know I'm not worried about him; I'm worried about another driver who just doesn't see him.

Sam did not find the O&M services Guillermo received very helpful. He is not sure that he will request these services again. He states that he relies on Guillermo's vision teacher to guide him regarding services that are needed.

*The importance of sports.* Guillermo has both visually impaired and typically sighted friends, but spends most time with his sighted friends. He makes most of his friends on his sports teams or while engaging in other physical activity, such as biking or Cross Fit, as discussed above.

Risk-taking, toughness, and pushing limits are topics that rise frequently in Guillermo's interview. He discusses how his participation in sports may affect his visual condition.

I'm honestly, like, I'm really aware of what's happening and I know what would happen if something went wrong with my eye. And I guess like that's another thing: when it comes to my schoolwork and my biking and lift weights, is I take things a step further. And rugby, someone with my eye disease would not ever want to play rugby or ride a bike around his whole town for safety precautions obviously, but, um I don't know, I'm just, I don't know. It's just something I really wanted to do and I felt like I had to do it.



Guillermo is comfortable with his decision to play a contact sport although he states that he is aware of the dangers. He relates the results of his most recent visit to the ophthalmologist.

I think it's all working out well for me right now. I had my last recent check-up and my doctors don't know I've been playing either. Everything's been the same for my eye since before rugby came along. And like, the cataract I had in my left eye, it's actually completely moved away on its own.

Guillermo states that his relatives had reservations about his playing sports. His grandfather still doesn't know he plays. Some cousins were supportive and although he states his father is now, he says his father was skeptical at first because of the roughness.

Most of Guillermo's friends play sports and the fact that at one time Guillermo couldn't, resulted in the loss of friends. His father relates,

He had...a core group of friends. But as he started getting a little bit older... Some wanted to go play baseball, a lot of them went to go play football, you know, they all kind started to splinter off. And they didn't talk to Guillermo anymore because Guillermo wasn't a jock...didn't play football... didn't run track. ... they just quit talking to him.

Sports were important to helping Guillermo develop and keep friends.

*Protection and freedom to grow.* Sam described tension he felt between needing to protect Guillermo and knowing he needed to allow him to mature. He relates that finding information and help with Guillermo's vision condition was difficult at first and

that he had to work to locate knowledgeable physicians. His reaction to learning of his son's condition was one of protection. "My initial reaction was to...follow him around, don't let him do anything because you can't get a tear, his retina will tear..." As time moved forward he realized he had to allow Guillermo to take risks.

Yeah, he's a big kid but he couldn't play sports, you know, and he wanted to play football; he wanted to play sports but he just couldn't. Because he would risk losing all of his vision for that. How do you keep a little boy from wanting to be a little boy?

Sam also had to weigh the benefits of team contact sports participation against the risks to Guillermo's vision, along with conflicting medical recommendations, "...his retina specialist says 'it's OK-- be careful.' His glaucoma and cataract specialist said 'don't'." He experienced tension, because he didn't want to compromise Guillermo's vision but also didn't want to compromise his sense of self-worth and opportunities to participate in the activities that are important to his peers. He feels that allowing Guillermo to participate has been beneficial to his self-esteem and enabled him to learn to socialize.

Just as Sam struggles with giving Guillermo the freedom to participate in potentially risky physical activities, he seems to struggle a bit with allowing his son the freedom he needs to discover his own interests while still providing the guidance he feels he should as a parent. He describes allowing Guillermo's experimentation with different 'looks' from preppy to skinner, and with various activities from skateboarding to golf.

In addition, Sam tries to find a balance in guiding Guillermo regarding his visual condition in general. He feels his son had difficulty accepting his visual condition. Sam feels it may help his son's sense of acceptance if Guillermo would talk about his vision impairment with others who have visual impairments. However, he notes that Guillermo is not inclined to talk about it much.

When asked for advice for professionals working to promote social participation with teens who have visual impairments, Sam suggests that professionals try to help their students and clients understand their visual conditions. It would be useful if teens who have visual impairments talked to each other for support and information but he finds that they often don't want to do so. He feels acceptance and understanding the visual condition are key to promoting social participation.

*Like but not like others.* Guillermo says that his activities are very much like those of his typically sighted peers. Most of Guillermo's friends are typically sighted although he knows other visually impaired teens. Guillermo relates that he participates in typical activities for a boy his age including school, sports, and dating. Guillermo says he thinks his responsibilities around the house are similar to those of his sighted friends but when asked if he's ever discussed this with his friends, he says "no". It just seems like something they do." He describes himself as basically shy but says that he learned to overcome that with maturity. Although he used to be a bit embarrassed by the accommodations he needed in school (sitting toward the front, using large print), he knows those things help him and now doesn't mind using them.

Sam, however, expresses concerns about his son's social participation. He doesn't see Guillermo having close friends. Until he became involved in sports, he was not interested in school-based extracurricular activities. He relates that earlier Guillermo was bothered by his appearance as a cataract made his eyes look different. "I think he developed not being very sociable because of that." The concern extends to Guillermo's relationship with his girlfriend. He describes a peripheral relationship. Although Guillermo dates, a typical activity for his age, "...they don't have a relationship like your typical, you know, relationship where high schoolers would have." Sam says Guillermo and his girlfriend don't see each other often, usually only at a monthly or so church youth group, and that their contact is primarily by phone or text.

Sam expresses concern about his son's performance in school. Although he says Guillermo is bright and likes school, Sam says Guillermo often doesn't turn in assignments. He does homework only at school with a group that meets for that purpose. He is concerned about Guillermo's approach to school assignments and says that the two struggled with that. However, Sam relates that he's talked with other kids who are on the rugby team with Guillermo, seniors who have been accepted at top universities, and that he has discovered that few of them turn in homework either. He decided to step back a little on this issue. Sam identifies his son's vision teacher as a primary support for Guillermo at school and for himself. He has great respect for the certified vision teacher who has been working with Guillermo since preschool.

*Guillermo and Sam summary.* Sam views his son differently than Guillermo presents or views himself. For instance, Guillermo initially describes himself and thinks he is seen as outgoing. Although in his second interview he qualifies that view, “I’m pretty, like, my parents say I was always pretty shy. But yeah, I’m a social person but I think I’m more shy than I am social and uh maybe it’s gone away.” Sam, on the other hand, describes him as shy and attributes the development of his shyness to his eye condition.

Guillermo and his father seem to view his dating behavior differently. Where Guillermo casually presents that he has a long-term girlfriend, “I have been dating this girl for a little over a year,” and in fact says he joined a church youth group because of his girlfriend, his father indicates that the relationship is rather peripheral.

Guillermo and his girlfriend see each other at a church youth group a few times a month. His father says they don’t see each other much otherwise. Their other contact is via telephone. When asked if the girlfriend is typically sighted, Sam says yes, then adds, “but you know if you were to see and talk to Guillermo, you really you can’t tell that he has a vision problem.” He justifies the reasons a typically sighted girl would date a visually impaired boy: he doesn’t *look* impaired. While one could conclude from this that Sam sees his son’s visual impairment as causing him to be inferior to a typically sighted person, this was not the impression I developed. In my field notes I wrote, “...he [Sam] is proud that his son functions well in the typically sighted world”

Both Guillermo and his father identify mobility issues as barriers but do so in different ways. Guillermo discusses wanting freedom to go where wants, and finding that with his bicycle. He gets car rides from his father and friends when needed but feels limited and knows he will not be able to drive. His father, on the other hand, feels his son's independent travel in the community is unsafe.

...every time he steps out that front door and goes for a bike ride, yeah, it really bothers me, you know? Just crossing the street where there's a light you know?

Hey, you know, I'm not worried about him, I'm worried about another driver who just doesn't see him.

One area in which Guillermo and Sam agree is the importance of team sports. As stated earlier, Guillermo and his father place a great deal of importance on team activities. Perhaps because of this importance, both father and son are willing to take risks with Guillermo's participation in rough sports. Guillermo expresses a teenage bravado, a sense that although catastrophic things can happen, they won't happen to him. He uses his eye exam to support his outlook. He notes that family members have concerns about his playing rough contact games but views their worries simply as barriers to his participation. He seems a little amused at his grandfather's concerns and takes a little pride in dismissing them. He wants to be seen as a risk taker and sportsman, a typical kid. Sam tries to balance the risk of participation with the benefits. He wants his son to mature into a responsible and independent young man and views social participation as a means of fostering this.

**Hal and Connie.** Hal is a 16 year old boy who was diagnosed with a tumor of the optic chiasm when he was 5 years old. He was typically sighted until then. He has no vision in his right eye and his left eye acuity varies, per Hal and his mother, between NLP (No Light Perception) and HM (Hand Motion). Functionally, Hal says he can see light and shadow, movement at a few feet, and color. Hal attends public school and receives services from a certified vision teacher. He received school-based O&M in the past but now receives it through a community agency, per his mother. Hal is involved in school-based extracurricular activities as well as in a variety of community volunteer activities. He also holds a paid job. Hal described (in his member check session), multiple hospitalizations and brain surgeries that occurred between ages 5 and 11; however, he preferred to talk about current and future events. The interviewer felt it important to respect this and did not push discussion of early events beyond what Hal volunteered. Hal's mother, Connie, shared that he has recently been diagnosed with myelodysplastic syndrome and is waiting for a bone marrow transplant. Hal lives with both his parents in a mid-sized city.

As can be seen in Table 5 and Figure 13, Hal's Overall CAPE scores indicate that he has a moderate level (36 of a possible 55) of diversity of activities with a relatively low level of intensity and moderate enjoyment.

*Hal's CAPE and PAC findings.* Table 5 presents Hal's CAPE and PAC data in numeric form.

Table 5

*Hal's CAPE and PAC Data*

	Diversity	Intensity	With Whom	Where	Enjoyment
Overall	36	2.7	2.7	3	3.8
Activity Type					
Recreation	9	3.5	2	1.7	4.1
Physical	7	1.6	2.7	3.4	4
Social	10	4	2.9	3.1	3.8
skill-based	2	0.9	2.5	3	5
self-improvement	8	4	2.7	3.8	3
Domain					
Informal	30	3.3	2.4	2.7	3.6
Formal	6	1.5	3.5	4.1	4.1
PAC	Overall	Informal	Formal		
	1.9	1.9	2		



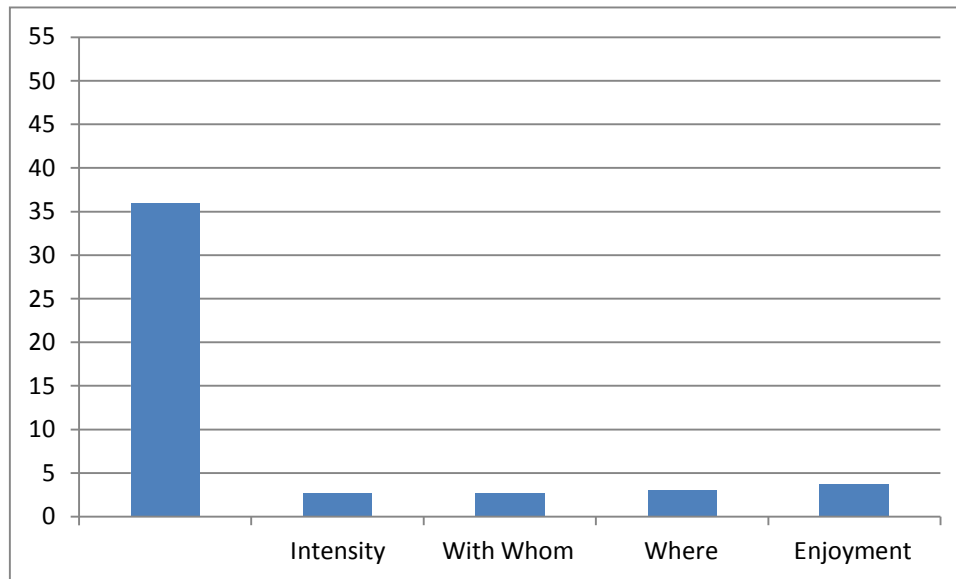


Figure 13. Hal's CAPE Overall scores.

In Figure 14, it can be seen that Hal's Activity Type scores indicate he participates most in social and recreational activities and that he enjoys these almost equally. Hal enjoys physical activities almost as much as he does recreational activities, but he reports a lower diversity and intensity of participation in this category. The intensity levels of social and self-improvement activities are the same, but Hal enjoys self-improvement activities less than social activities. Activity Type scores also reveal that Hal enjoys skill-based activities most but participates in these the least.

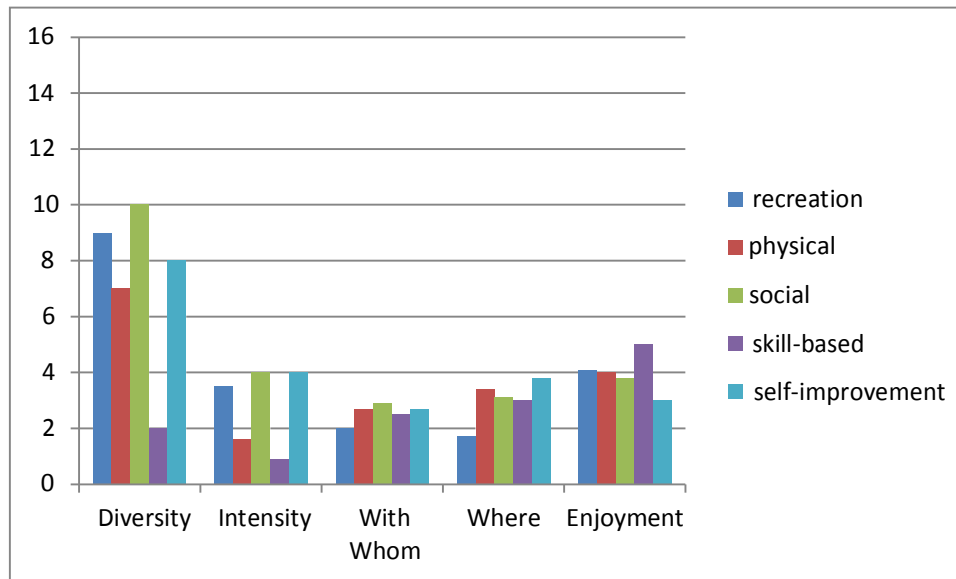


Figure 14. Hal's CAPE Activity Type scores.

Figure 15 shows Hal's Domain scores. It can be seen that Hal participates more frequently and in more types of informal than formal activities, however he reports that he enjoys Formal activities more than informal. Hal's formal activities take place farther from home and with a wider range of people than his informal activities.

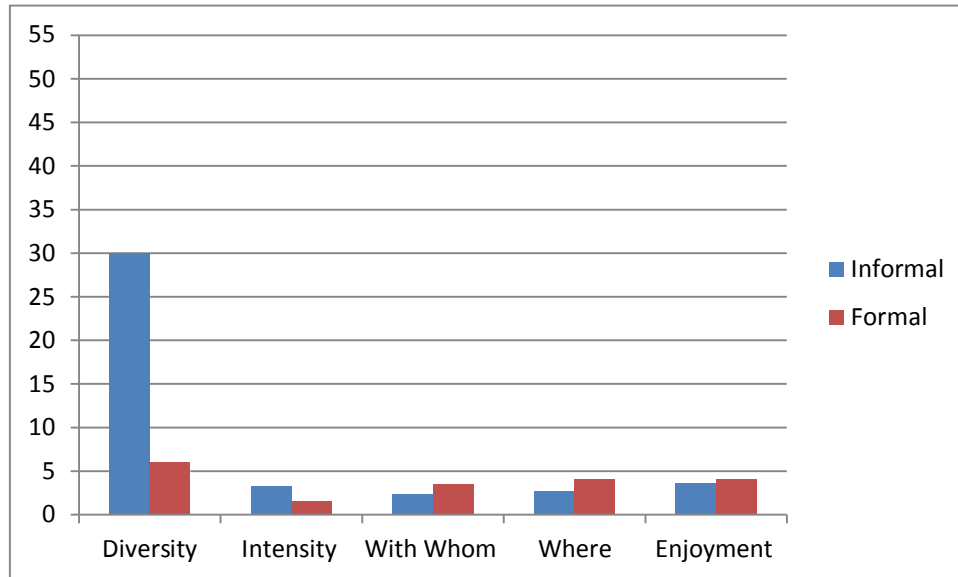


Figure 15. Hal's CAPE Domain scores.

In Figure 16, it can be seen that Hal reports a preference for formal over informal activities. This is consistent with his CAPE Domain scores.

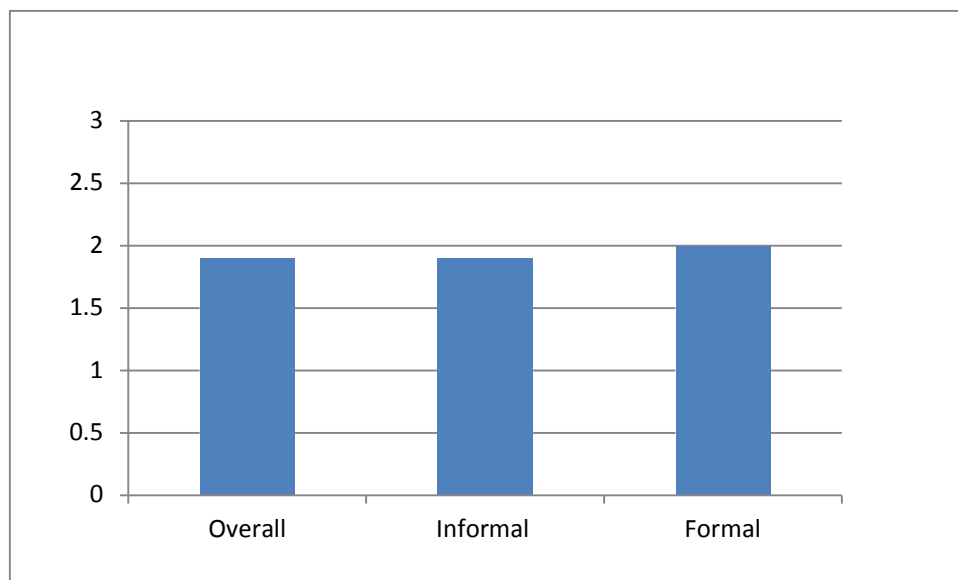


Figure 16. Hal's PAC scores.

The low intensity score noted in Hal's participation in activities may be explained by data from his mother's interview. Connie described overlapping schedules of various activities, particularly debate team and goalball, which often conflict, requiring Hal to make a choice between the two. Although Hal is interested in a variety of activities, he doesn't engage in any of them as frequently as he would like. Data from Hal's member checking visit explain Hal's more frequent engagement in informal activities although his CAPE and PAC scores indicate a preference for formal activities. Activities categorized by the CAPE as formal include swimming, participating in community organizations, playing a musical instrument, and doing team sports; these are things Hal has done in the past but has chosen to limit so that he may participate in debate and his job.

*Thematic analysis.* Three themes emerged from Hal's and Connie's interviews. These include: "Seems the same but isn't," "Getting around," and "Protection and freedom." "Seems the same but isn't" emerged from discussions about Hal's participation in various social activities including dating. It includes "activity versus engagement" and "social participation barriers and supports" as subthemes. "Getting around" emerged as theme as Hal and Connie discussed his functional mobility issues and how they affect Hal. "Protection and freedom" includes Connie's described conflict between wanting to protect and knowing her child needs to have autonomous experiences.

*Seems the same, but isn't.* Hal is busy, like most teens his age; he is on his school debate team, plays goalball, and is on the board of a national organization of blind students. He enjoys swimming and camping but says he doesn't get to do those much. On

quiet evenings, when there is nothing interesting on television, he enjoys playing guitar or other musical instruments, or exercising. He has participated in the National Braille Challenge seven times. Hal volunteers with Make-a-Wish, Miracle Network, and St. Baldrick's fundraisers. He also has a paid job with a technology company, testing applications for accessibility. He works from home and is able to choose which and how many jobs he takes on. Hal wants to be an engineer and believes the activities he does through his job will help him achieve that goal. Hal also has cancer. He is waiting for a bone marrow transplant.

His friends are a mix of typically sighted and visually impaired youth. Hal explains that he knows more typically sighted peers as those are the ones with whom he attends school. He doesn't get to spend as much time with his blind and visually impaired friends, whom he sees mostly at organized events for visually impaired teens. Hal feels his activities are very much like his typically sighted peers. At the same time, Hal also feels he's often left out of social activities and that he has fewer experiences in general.

At school, I... hear about some party that happened over the weekend... the next week rather than the week before it happens. I hear about it afterwards... So that's one difference, is that I've never been to any of these parties... another one is, well, the fact that I can't drive. I don't drive myself, I don't have all the interesting experiences of driving home from school...

Hal believes the lives of his typically sighted friends are easier than his. He admits to feeling a little jealous of the ease they experience and of what he considers minor problems.

I'm, a little, well, envious of my sighted peers... because their problems are,...rather than trying to figure out how they're going to get an assignment done because it's on an inaccessible website, all they're worrying about is, you know, "Oh no, I woke up late and traffic's really bad so I'm going to be late for school..."

Hal feels his typically sighted peers have more control over their lives than he does. He states he hasn't really checked with his typically sighted friends to verify that things are easier for them. He gets the sense that they don't want to talk about it or that they're uncomfortable.

Connie has concerns about Hal's social participation. She describes Hal as "not popular, but well-liked." She feels he is a leader and that he has an understanding of others. Yet, "...he doesn't socialize as much as I would like him to." Although Hal does participate in after school activities including debate, goalball (when it doesn't interfere with debate), and a monthly support group for visually impaired teens in his area,

...there are a lot of times that he just sits at home...he tends to do stuff with us and I'd like to see him going out with the kids and everything but I don't know. It's probably not as bad of a problem as I think it is, but it does bother me because I know when I was in high school, I was going and doing things all over the place, you know?

*Activity versus engagement.* Hal's mother states she isn't sure if Hal's social activity level is the same as his typically sighted peers'. She does note that his activities are a bit different than theirs, however. For instance, she knows that other kids are in the school band and that her son talks about parties others have attended. Other kids go to school dances, but Hal has made it clear that he doesn't like to dance nor the noise level or music played at the dances. She states that when he was in junior high she insisted he go to school dances,

...and he'd spend most of the time in the office talking to some of the teachers (laughs). And that just bothers me, you know? I'd rather him being, do things with his peers rather than the teachers, but, oh well (laughs).

Connie feels that finding a sense of belonging and reciprocity has been a challenge for Hal. She was happy when Hal chose to return to the debate team after being away from it for a time "... because that actually meant he made a connection with a group of people, you know?"

She had been worried that Hal was having difficulty finding a group of peers with whom he could identify. In fact, Hal's mother perceived that he was set apart; he was "The Blind Kid" whom everyone knew and liked, but he did not have the reciprocity involved in friendship. She knows his physical presence at school has not resulted in his meaningful participation in the social life of school: "...a lot of times he's kind of almost like a celebrity (laughs)..., he's the blind kid, you know, and everybody knows him, but he doesn't know that many people."

Connie is pleased that Hal has been interested in dating. He has gone out with three different girls. Connie is not sure how ‘typical’ his dating behavior or that of his girlfriends is. The first girl seemed to use him for the status of being in a relationship rather actually engaging with him as a person; even when she repeatedly turned him down for dates, “she still told everyone they were dating.” Regarding the second girl, Connie thinks Hal may have misinterpreted her signals initially and that she really only wanted to be friends. With the third girl, Connie thinks Hal’s self-consciousness may come into play. In addition, she is not certain about the depth of their relationship “I don’t even know how to say this— I don’t know do they hold hands or do they kiss good night, or anything like that, you know? I don’t know if any of that stuff happens.” Of note, although Connie spoke extensively about Hal’s dating, Hal did not mention it at all.

*Social participation barriers and supports.* Even with his involvement in the debate team and dating, Hal’s mother feels that Hal participated in more social activities before he was in high school. She attributes this increased activity to his involvement in a church group and working toward religious confirmation. She also describes social barriers she and Hal encountered at the church which she thinks led to his decision not to participate. “But now he doesn’t do much with church ... though that might be because a lot of their activities are very visual and he just doesn’t feel like it... he just feels like, what’s the point...” She tried to intervene and explained to the church group what Hal needed. The group did try some things but the effort wasn’t consistent. In addition,



Connie questions whether it was reasonable to expect an entire group to make accommodations for one child.

...there comes a point where they say, 'ok they've got 5 kids or 10 kids or however many kids it is, and one of them's blind' –so you can't always expect them to not do things that are visually oriented.... just for him. And we understand that, you know. So, and sometimes they try, and they kind of miss the mark, you know? They aren't thinking about... he's not really getting anything out of this.

Connie also described barriers to Hal's participation at school. Most barriers have been related to access to information. Interestingly, she seems to view these barriers more as institutional artifacts than social issues. She expects that these barriers will be present and accepts it.

...probably any barriers he's encountered really kind of come down to are that they're visual and people are not willing to accommodate it. And... this is not necessarily social, this is more like part of school.

Hal had an AP math teacher who refused to make accommodations for him. He describes the experience:

... in 10<sup>th</sup> grade, my pre-AP Algebra 2 teacher would not get materials brailled in time and so ... what everybody else had done 3 weeks before, I'd get it along with everything else up 'til then. And so I'd go for weeks without anything to do in that class or homework-wise or anything and all at once I would have a ton of

work to do... Also, he wasn't so keen at getting the quizzes and tests brailled and so he had me take a couple of quizzes auditorally - and for math that's really difficult.

Connie notes the limitations these barriers have imposed on her son. "He's pretty good with math. And if he were not blind I think he would be doing all pre-AP and AP math classes." After making attempts to change the situation, Connie, Hal's VI teacher, and Hal decided to drop it. She states,

... it all comes down to they say the pace is so fast you can't keep up. Well I don't think that's true, I think it's that they aren't providing the information in a manner he can follow, you know. So, but you kind of choose your battles.

The family chose not to fight further and made adjustments. Hal was removed from the AP classes. Hal's mother recognizes that this decision may have lasting effects on Hal's plans for college. College may take longer as Hal won't be entering with the in-depth math knowledge he would get from AP. She is trying to be comfortable with this.

In contrast to the barriers the family has encountered, Connie and Hal also identify many supports. Connie states, for instance, that Hal's current physics teacher welcomes Hal and treats him well, making all necessary accommodations. She also states that Hal's vision teacher has been a primary support throughout his school years. Hal has attended many specialized programs sponsored by DARS Division for Blind Services, the Texas School for the Blind and Visually Impaired, out-of-state programs for independent living and career exploration/work skills and Connie and Hal identify these as supports to

participation as well. Notably, Connie identifies the other students at school as supports as well.

I've been impressed throughout his years of school, because I've always had this, you always hear about the bullying and things like that, and I know that throughout ...school those kids, they took care of him, they really looked out for him... Now we've talked about this several times because some of his visually impaired friends will talk about being bullied and stuff and he's like, "I don't understand... I don't experience that."

*Getting around.* Hal describes himself as a good traveler. His mother also states that his Orientation and Mobility (O&M) skills are good. Hal has had O&M instruction through school although he does not currently receive O&M instruction at school. "Actually...since he's been in high school he really doesn't need that much... we've really had to think up things to work on because he's pretty good at your basic O&M skills."

Hal relies on his parents however, for transportation to his activities. He does not use public transportation. His reliance on parents for transportation affects his social participation options. Connie recognizes this in relation to Hal's dating experiences, "I think one of the things that he has a little bit of a problem with is that he feels strange, you know, with his parents picking them up and dropping them off..." During member check Hal agreed that he felt self-conscious sometimes when his parents drove him

places. Also during member check Hal expressed that he was a bit envious of the freedom and independence his peers found in driving.

*Protection and freedom.* As Connie reflects on Hal's and her own experiences, she discusses some of the difficulties and uncertainties she faced and how she addressed them.

...as I was adjusting to him being blind, I would have these nightmares about certain things, you know, about how's he going to do this? So I would try, I worked really diligently to make sure that he got the training he needed because I didn't always know how to train him, you know, but I could get him in to classes and things like that they would be able to teach him how.

Several times during the interview she discusses the conflicting feelings of wanting to protect Hal and knowing she needs to allow him freedom to experience things on his own. Connie describes learning to step back and allow Hal social freedom.

One example for when I learned, kind of reinforced this with me, was one of his first debate tournaments. We went up there to, you know, show our support and everything, and I noticed that he had been sitting at a table with kids and while we were there he just sat with us... I said, 'Hal, would you like me to leave so that you can have time with your friends?' and he said, 'Well, yeah really I would.' (laughs). So I did, I left, and so that's one of those things where I think parents need to understand that the kids, ... you can't protect them from everything, they need to be able to handle life on their own.

Even knowing he is capable, she worries about him being able to manage at college. Hal has attended multiple specialized programs to learn independent living skills and he routinely uses these skills at home. He is good at O&M skills. Still,

...those are some of the things I do wonder about the O&M aspect of it. He would like to go to Texas A&M which is a fairly big campus... So I'm a little concerned about how is he going to learn all the buildings and everything, you know?

She takes some comfort in understanding that her feelings are not very different from other parents':

But...what I have been told by other parents, is that that's really not a thing for blind kids, exclusively, that all parents have that feeling like how will my kid survive? So that makes me feel a little bit better, that I'm being a natural mother but...I think that if I had a sighted kid, I'd be saying 'at least they can see to get to the bus stop', or see to get to the different buildings, you know?

***Hal and Connie summary.*** In summary, although Hal clearly is interested in all his causes and activities, some of his activity seems like a search for engagement. For instance, although Hal is clear about his goals for the future and has a strategy to achieve them:

I'm working hard to keep my grades high so that I can be accepted into a good college.... I'm also doing all these extracurricular activities so that colleges see that I'm balanced and my activities –I'm not just doing school related stuff.

Hal seems much less clear about how to make and keep friends and how to develop a social group. Asked during his interview how he makes friends he says “I go to school and talk to people.” Hal seems to know how to construct expected appearances but may not yet have learned how to build the substance of his experiences.

Connie expresses concerns about Hal’s social participation, as well. She feels finding a sense of belonging and reciprocity has been a challenge. Of note, although Hal’s mother spoke at length about his dating experiences, Hal never mentioned that he dated during his interview. Whether this was because of self-consciousness in discussing dating with a relative stranger (the interviewer) or because he was not truly engaged in the dating even as he superficially participated in it, was not determined. Connie and Hal have encountered both supports and barriers to his social participation and tend to focus on the supports.

Hal’s social participation is important to Connie as she sees it as the basis for his successful transition to adulthood. Hal views social participation as part of what gives his life satisfaction and meaning and that will allow him to be a “happy, productive member of society.”

**Seth.** Seth is a 14 year old boy with a diagnosis of Leber’s Congenital Amaurosis. He has no light perception. He attends public school and receives services from a certified teacher of visually impaired children (VI teacher, or Vision teacher) and a Certified Orientation and Mobility Specialist (COMS, or O&M). Seth participates frequently in

goalball and enjoys computer coding. He maintains a website and blog and has done so for three years.

Seth completed the CAPE and PAC face-to face with the researcher. His interviews took place over the phone. Seth lives with parents and his sister, Lisa, who also has Leber's, in a suburb of a large city.

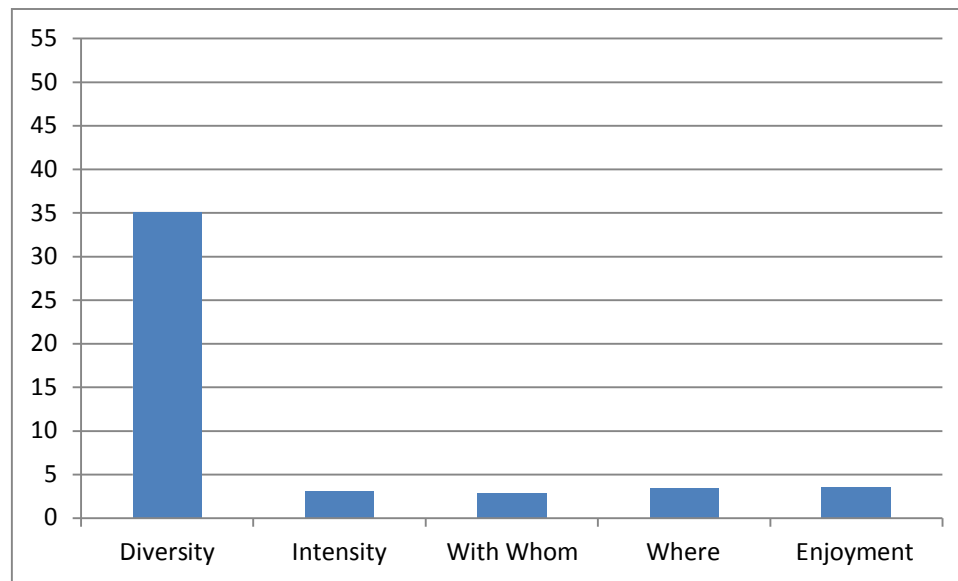
*Seth's CAPE and PAC findings.* Table 6 presents Seth's CAPE and PAC data in numeric form.

Table 6

*Seth's CAPE and PAC Data*

CAPE	Diversity	Intensity	With Whom	Where	Enjoyment
Overall	35	3	2.8	3.4	3.5
Activity Type					
recreation	8	3.3	2.5	2.5	4.2
physical	6	2	2.3	4.5	3.8
social	9	3.8	3.2	3.7	3.8
skill-based	5	2.5	4.8	4.8	1.8
self-improvement	7	.9	1.7	2.1	3.4
Domain					
informal	28	3.6	2.3	3	3.8
formal	7	2.4	4.8	4.8	2.4
PAC	<u>Overall</u>	<u>Informal</u>	<u>Formal</u>		
	1.6	1.6	1.9		

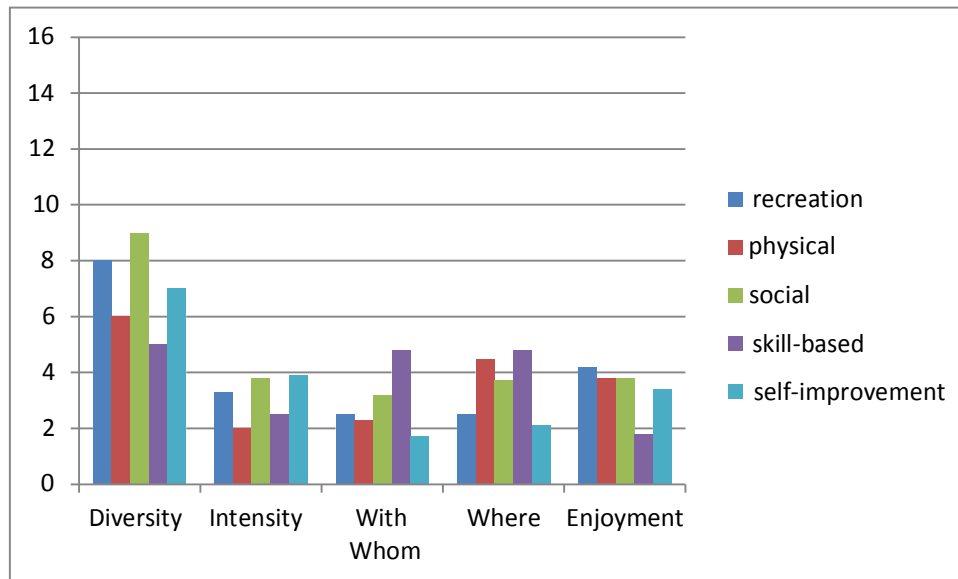
As can be seen in Figure 17 and Table 6, Seth's CAPE Overall scores indicate a moderate diversity (35 of 55) of activities with a relatively low intensity (3 of possible 7) of engagement. His enjoyment level score is moderate (3.5 of possible 5).



*Figure 17. Seth's CAPE Overall scores.*

Seth's Activity Type scores, seen in Figure 18, indicate that Seth participates most frequently in self-improvement activities but that he enjoys recreation activities most. His broadest range of activities (diversity) is with social activities. He participates in physical activities least frequently of his activities but he reports higher level of enjoyment for physical activity than for skilled based or self-improvement.





*Figure 18. Seth's CAPE Activity Type scores.*

In Figure 19, it can be seen that Seth's CAPE Domain scores indicate he has a greater diversity of, engagement in, and enjoyment of informal than formal activities. His formal activities take place with a wider range of people and farther from home than his informal activities.

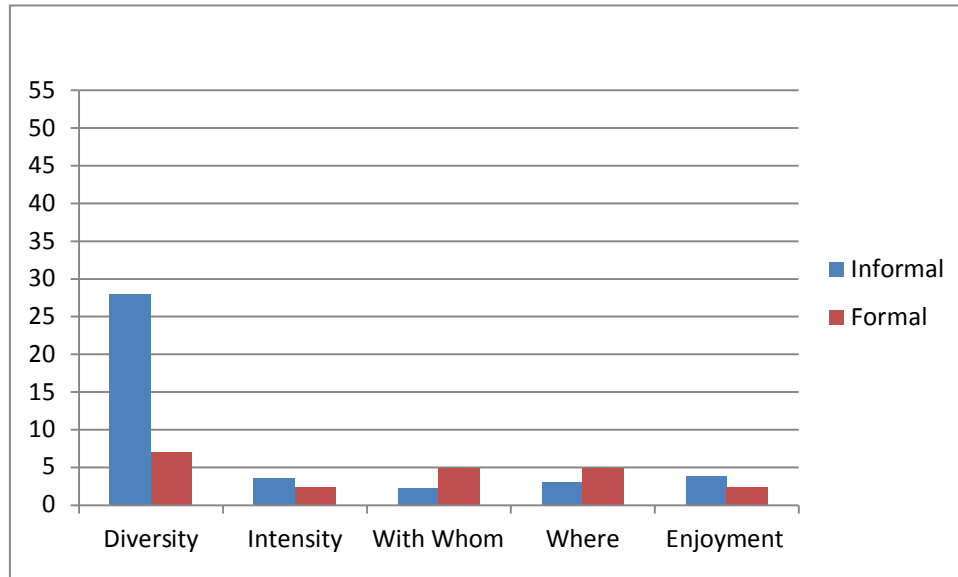


Figure 19. Seth's CAPE Domain scores.

Figure 20, it can be seen that Seth's PAC scores also indicate a slight preference for informal over formal activities (a difference of .1). His PAC Overall score indicates a relatively narrow range of activity preferences.

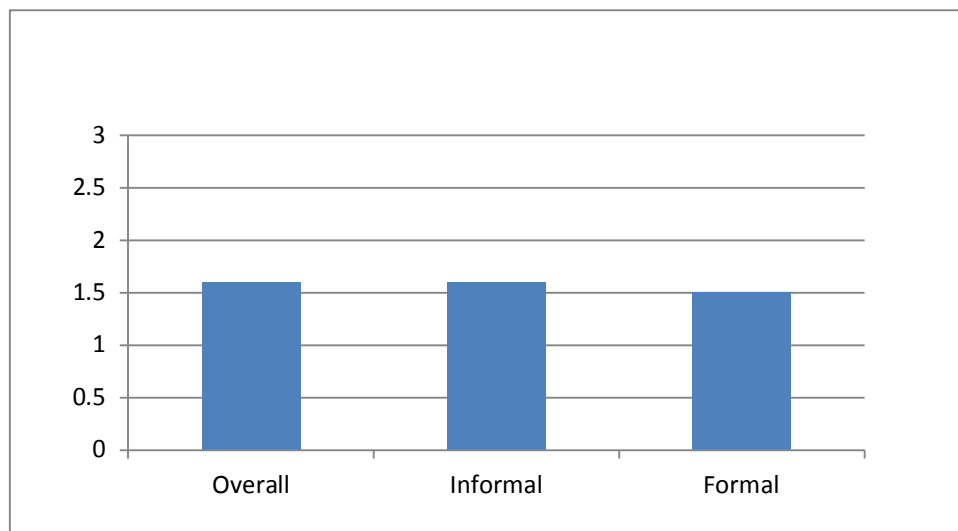


Figure 20. Seth's PAC scores.

Seth's scores indicate most frequent participation in self-improvement activities but higher enjoyment of recreation activities, which can be explained by the types of activities categorized as each. The CAPE includes chores, homework, and religious activities in the self-improvement category. Seth reports during his interviews and directly on the CAPE that he engages in these daily, or several times each week. These are activities he is required and expected to do, rather than those he has chosen for himself. Therefore, it makes sense that he would report his enjoyment level for these at a lower level than those he freely chooses.

***Thematic analysis.*** Three themes stood out in Seth's interviews. These include: "The need to know," "Influence of friends," and "I'm my own person." "The need to know" deals with Seth's statements about revealing and not revealing information about his visual impairment and to whom. "Influence of friends" emerged from Seth's discussion of the ways he developed his interest in recreation activities and identification of possible career goals. "I'm my own person" emerged as Seth discussed his approach to peers and expectations of adults in his life.

*The need to know.* Seth shares his insight that he doesn't tell many people about himself. His friends know what he allows them to see. He says he maintains a mix of both typically sighted and visually impaired friends. He likes talking and hanging out

with them. Asked during the second interview how he tells others about his visual impairment he says,

I don't really tell people about it. I just assume that they'll know about it or they won't, unless there's an absolute need for it. (And if there is a need), I just tell them I can't because I can't see. Usually that never happens because they'll see my cane and that I'm not looking at them, and they should be able to gather that I can't see.

Seth identifies a need to tell as, "If they ask me to participate in something I can't participate in, because I'm blind."

Even in dealing with his teachers, Seth indicates that he talks about accommodations he needs but not about his visual condition specifically. "Well I have to tell them but just about accommodating the work so I can do it." He states he and his vision teacher share responsibility for informing teachers but that his vision teacher usually initiates the process by talking with teachers prior to the start of the school year.

*Influence of friends.* Seth states that one of his main interests is computer coding. He first learned about it.

...programming, well, 'cause, you know, I got on this forum of blind people, it's like an audio gaming forum. And I learned about them. So a type of game which is like basically video games but instead of video it's got audio...And so, I was, like, fascinated with that. And I was like, man, I want to program that and then

...the more I started tweaking software, the more I was like, 'this is cool', I hope to create some of it and that's just been something I've always wanted to do.

Seth enjoys computer gaming. He knows his fellow gamers from the Texas School for the Blind and Visually Impaired and from Sports Extravaganza, where he met them. Seth states that his gaming friends interested him in programming as a possible career and he is currently learning how to program with them. He acknowledges that his social interest in gaming has helped him arrive at this career interest. At his second interview, Seth is even more involved with gaming than he was in the first interview and he has learned how to code. He is developing games with his friends. Asked if he thinks he would like this to be his career, he answers, "Yeah. It probably won't be game developing, but it's a start... Oh if there was a game development job, I'd take it." He identifies a barrier:

Well... a lot of it is graphical. And I prefer to work at my own pace because with my games, I come up with the ideas and write them exactly how I want them to be... That would probably be a side hobby or something. Like coding, I do want that to be a career.

Seth has thought about a career choice that he learned about from friends. He recognizes possible barriers to achieving his goal but has identified an acceptable alternative. His gaming and coding continue to be a social outlet as well.

*I'm my own person.* Seth describes himself as moderately independent but needing a little help sometimes. He says he needs most help in orientation and mobility.

“I can do a lot of things by myself, but there are still things that—like, I need help around places... I don’t remember how to get to places” He uses a long cane for mobility. He relies on his parents and friends for rides to events like goalball practice and Sports Extravaganza.

Seth has responsibilities at home and is proud of them, “Well, at home I have to clean my room and I have to help clean the bathroom upstairs and I have to do the dishes and feed the animals.” Asked if he thinks his responsibilities are similar to other kids’, he answers

I don’t know. That’s never really something I’ve brought up in conversation. I mean, I’ve asked a few other blind people and no, unfortunately, the way some of them are brought up and everything, they’re not able to do that sort of stuff, so...I mean, I don’t know what the other ones do because, like, my [typically sighted] friends at school and all them, I’ve never asked them. I never, in fact, I’ve never even asked a lot of the blind friends that I’ve really talked to.

Seth is aware that he has more skills for independence and has more responsibilities than some of his blind peers. He thinks it is unfortunate that they are unable to do as much as he can. Even if he hasn’t directly discussed it with them, he has noticed a difference. His friends at school are typically sighted. He hasn’t discussed home responsibilities at all with them.

During the first interview, when asked if he had any suggestions for his teachers or other adults helping teens with visual impairments with social participation, he said “No.” When asked in the second interview, he said

Basically, I’d say, don’t force them because, in my perspective , being forced to and being told that I *have* to do this because it will improve my social skills, you know, basically all that does is make me resent the whole idea because, I’m being forced to. Still kind of *encourage* them, encourage them and come up with ideas of things to do that they would enjoy, you know, encourage them to hang out with their friends more but don’t force them because then they’ll be less willing.

***Seth summary.*** Seth understands and is able to explain his vision condition. His choice not to discuss it with others may be in part due to self-consciousness in general or due to a strong sense of privacy. His choice could also be explained by his own first interview statement at face value, he just doesn’t usually see a need to explain it past saying “I’m blind.” He feels the attention given to his blindness is unnecessary. It’s simply a part of who he is.

Seth does encounter barriers due to his vision but he doesn’t seem to see them as particularly important. If someone asks him to do something he can’t do because of his vision, he simply tells them he can’t because he’s blind. The other person should have known. If coding for games professionally is inherently a visual task, he’ll code otherwise and develop games on his own. Seth in this way seems truly his own person, adaptable and practical.

Seth is wary of being “done to,” of having things done to him or being told that he must do something because others know what is best for him. While this attitude could be an artifact of adolescence, it is important to also consider it in terms of the social constructs of blindness. Seth knows what he wants and who he is regarding his blindness. He doesn’t want or feel the need to be made “better.” To him, someone else’s idea of how he should behave is an imposition and within a social context, somewhat demeaning. Although Seth does not directly articulate this, much about him embodies it. Seth seems to be learning to manage autonomy.

**Lisa.** Lisa is a 16 old girl with a diagnosis of Leber’s Congenital Amaurosis. She has light perception only. Lisa attends public high school in a suburb of a large city and was a junior at the time of the first interview. She receives services from a Certified Teacher of Visually Impaired Children (CTVI) and in the past received Orientation and Mobility (O&M) services. In addition to her local school program, Lisa has attended programs sponsored by the regional Education Service Center (ESC) and short programs at Texas School for the Blind and Visually Impaired, which focused on Orientation and Mobility as well as life skills and work skills. Lisa has done community volunteer work. Although she states she has not yet held a paid job, she does sometimes work (for pay) for her father’s business, setting up bounce houses for parties. Lisa does well academically and is in the National Honor Society. Lisa lives with her parents and her brother, Seth, who also has Leber’s and who was also interviewed for this study.



*Lisa's CAPE and PAC findings.* Table 7 presents Lisa's testing data in numeric format.

Table 7  
*Lisa's CAPE and PAC Data*

	Diversity	Intensity	With Whom	Where	Enjoyment
Overall	43	3.3	3.2	3.9	3.6
Activity Type					
recreation	9	0.73	2.6	2.3	3.3
physical	10	2.6	4	5.4	4.1
social	10	4	3.3	3.9	3.4
skill-based	7	2.4	4.4	5.2	3.1
self-improvement	7	3.8	2.2	2.7	3.7
Domain					
informal	31	3.4	2.7	3.4	3.6
formal	12	2.8	4.5	5.2	3.7
PAC	Overall	Informal	Formal		
	2	1.7	2		

As can be seen in Table 7 and Figure 21, Lisa's Overall scores for CAPE indicate a high diversity level with relatively low intensity (frequency) and slightly higher level of enjoyment. Her activities are fairly balanced between solitary and group and home-based and community.

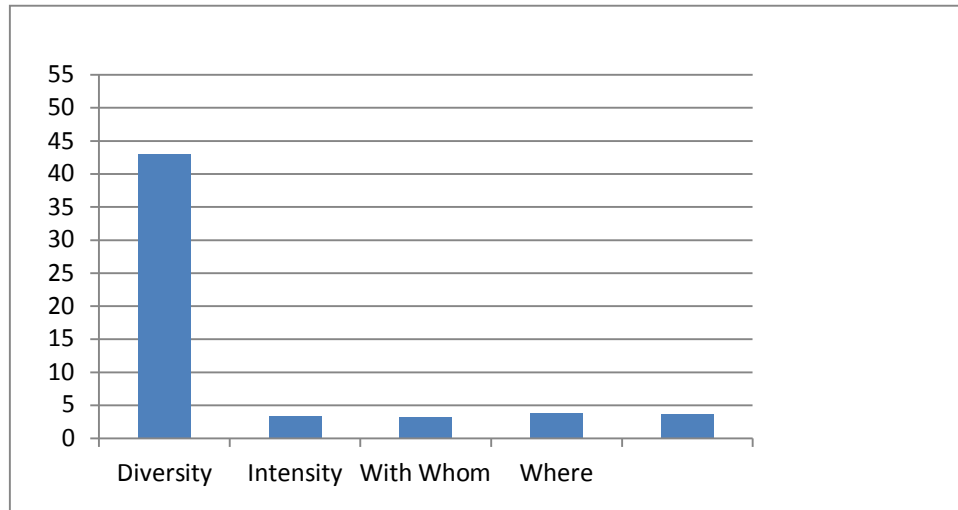


Figure 21. Lisa's CAPE Overall scores.

Lisa's Activity Type scores can be seen in Figure 22. Lisa's scores indicate that her highest level of enjoyment is with physical activities, although she participates in these less frequently than she does in activities in the social and self-improvement categories. She participates least frequently in recreation activities. Her physical activities take place farther from home than do her other activities.

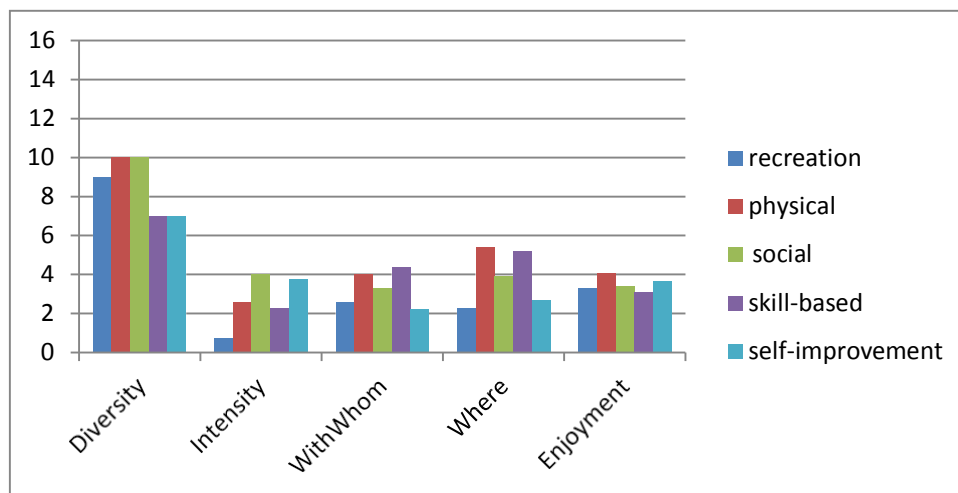


Figure 22. Lisa's CAPE Activity Type scores.

As can be seen in Figure 23, Lisa participates in a wider range of informal than formal activities. She participates in informal activities slightly more frequently than she does formal activities. She rates her enjoyment as almost equal for informal (3.6) and formal (3.7). Lisa’s formal activities take place with a wider range of people and farther from home than her informal activities.

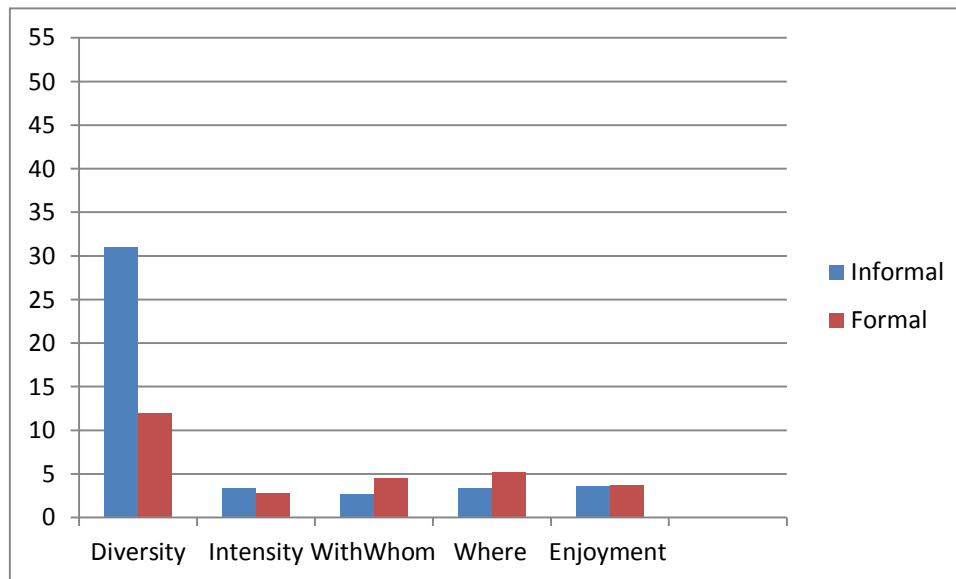
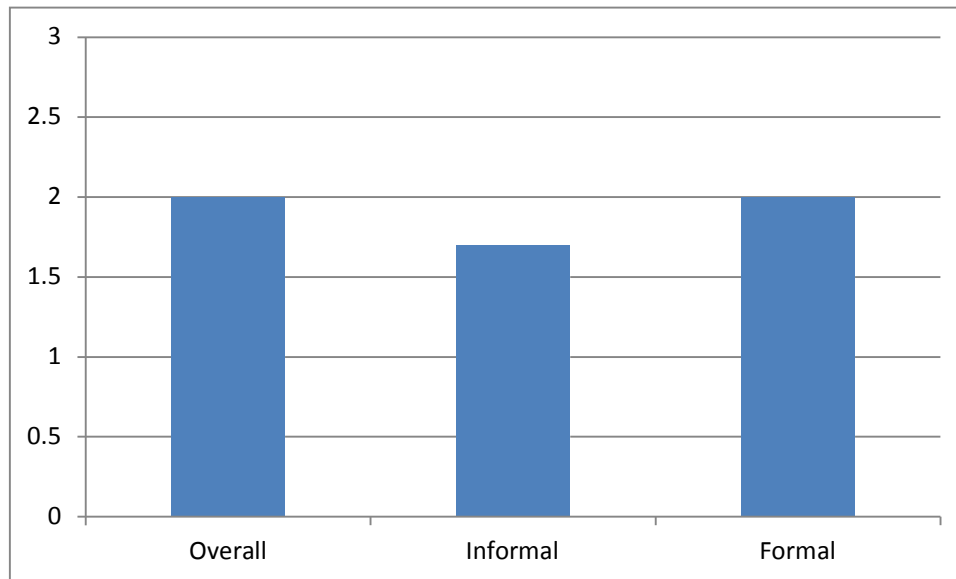


Figure 23. Lisa’s CAPE Domain scores.

Figure 24 depicts Lisa’s PAC scores. Her Overall score indicates a preference for a broad range of activities. Although her CAPE Domain scores indicate participation in fewer formal than informal activities (both *Diversity* and *Intensity*), her PAC scores indicate a preference for Formal over Informal activities.



*Figure 24.* Lisa’s PAC scores.

Information from her interviews supports Lisa’s CAPE and PAC data, including a preference for Formal activities. Lisa described a wide variety of interests and much enjoyment of each but spoke most about her experiences with her debate team, mock trial team, and student government at school. Lisa’s enjoyment of physical activities is also supported by her interview data. She reports she is involved in water sports, goalball, Cross Fit, and church activities. Most of her activities are formally organized although she states she also enjoys ‘just hanging out’ with friends.

***Thematic analysis.*** Three themes stood out from Lisa’s interview. These include: “Self-advocacy,” “Importance of being social,” and “Getting ready for the future.” “Self-advocacy” deals with Lisa’s initiative in addressing various barriers to her social participation and in using available supports. “Importance of being social” emerged from Lisa’s discussion of her initial shyness around others and how she learned to deal with it.

While talking about this, Lisa also provided some insight into how she views herself in relation to her typically sighted and visually impaired peers. “Getting ready for the future” includes Lisa’s perceptions of her activities as they affect her now and as they may help her achieve her goals as an adult.

*Self-advocacy.* Throughout her interviews, Lisa describes ways in which she advocated for herself when she encountered barriers to her social participation. Lisa stated that she expects to encounter barriers and manages them as they occur, “I definitely felt like I ran into a few difficulties. I mean, like, that’s just pretty much everything being blind or visually impaired.” Many of the barriers she has encountered are due to lack of access to information. For instance, she needs school and extracurricular materials to be brailled or in electronic format, but says

I either get it through braille or through e-mail but the only reason it’s difficult is, number 1, if it’s not typed up on a computer then it has to be typed up to get it in braille or I guess email, obviously, but you can’t braille it if it’s just handwritten. And, number 2 is, my software on my computer that I use to read, won’t read certain file types like PDFs so they have to convert it and some teachers, they don’t know how to do that.

Lisa also describes social participation barriers that occurred directly due to her vision loss. She is unable to see others’ nonverbal communication and did not immediately understand how to use nonverbal communication methods herself. She

found this especially important in terms of her participation in debate and mock trial activities.

... There's certain body language that you have to use and it's the same with mock trials, so I had to learn those things...I went and observed with my teacher and he told me certain things. And there were ways to by-pass the body language. I was able to request that any nonverbal communication used was verbalized by a person, like in Congress to start your speech, you ask them to nod to let you know that they're ready and so I would ask, "could you please...say something, you know, let me know when you're ready?" It was just, you know, getting around that.

Lisa dealt with difficulty understanding body language by seeking an adult mentor and suggesting to the mentor what she needed. She chose not to wait for an adult to offer help and none did before she asked.

Lisa has learned to access the resources available to her and she credits her vision teacher with helping her do this. Lisa's CTVI through public school provides needed technology and braille services to enable Lisa to access her school and outside programs. She helps Lisa advocate for herself and she acts as an intermediary for Lisa with her general education teachers. Community resources have also played a part in supporting Lisa's social participation.

In addition to difficulties posed by lack of access to information, either due to technology or due directly to her severe visual impairment, Lisa described barriers she encountered in interactions with her typically sighted peers.

... You run into certain difficulties...Like with the mock trial team: you only could have 6 people on a team and of course there were 20 people trying to get on the team. Some people were a little uncomfortable with the fact that I made the team and they didn't.

She had to overcome the suspicion of others that she made the team only because she was blind. In addition, she dealt with the discomfort of others that manifested in awkward ways.

...I might be sitting with a group of friends and a sighted person comes up and asks a question about you and they're right next to you...Or, you know, they'll try to be helpful but overly so, like going down the stairs, I've had people freak out and grab me or just, like, panic (giggles).

From my observation notes: Lisa takes the awkwardness she encounters in good humor although clearly she is also annoyed by it. She has a strong sense of autonomy and agency. Lisa expresses self-awareness and insight with others.

*Importance of being social.* Lisa describes her activities and responsibilities at home as very similar to those of her sighted peers. She also describes difficulties she overcame in learning how to interact with her typically sighted peers in social situations.

I think that a blind or visually impaired person, we're automatically shy and, like, nervous to see how other people feel about us or how they're going to accept us so we're automatically going to go, "...I don't want to attend that function or that after school activity because, you know, I don't really know anybody." But I think, like, if a parent or if a teacher, not necessarily force them, but be like you know, 'this will be really good for you. You will make friends.'... Because that's how it started out with me... I was always nervous to do stuff, but my parents kind of pushed me. Like, "you can either sit here at home or you can go do this and make new friends," and...I can do it myself now and say, "I can either sit here and be bored or I can go socialize, make some friends and be around people."

And

... I'm much happier with going after school and doing extracurricular activities or going out to eat with a group of friends where before... I would have...made up excuses not to go because I would have been nervous...You definitely realize how you view sighted people as not accepting you, and well, they're nervous, too. You realize that. And once you start going to these social events, you realize that they don't think of you as so much different, they're just as nervous as you are.

Lisa identifies her parents as primary supports for her social participation. They provide emotional support for taking risks and exploring social activities and interactions. In addition, it is her parents who encourage her to try a variety of physically active as



well as academically related activities. At the same time, Lisa recognizes that her parents may struggle, much as she does, with nervousness about letting her go into the community and take risks. When asked about her reasons for socializing, she states,

Well, like, I've noticed with other visually impaired and blind people, they're a little more nervous to be in social like, surrounded by people and sometimes they don't know necessarily how to hold up just a simple conversation...they tell each other stories about how they don't really have...friends. So it's definitely important to be able to just go and spend some time with my friends.

She notices the difficulties some of her visually impaired friends experience and compares herself to them. While she can relate to those who are 'nervous' in social situations, she defines herself as not like them.

While Lisa has both typically sighted and visually impaired friends, most of her friends are typically sighted because "my sighted friends are the ones who go to school with me and who go to church with me..." She has met her visually impaired friends primarily through activities organized by agencies for blind and visually impaired children and teens (goalball, Education Service Center events, Texas School for the Blind and Visually Impaired, and DARS Division for Blind Services). Because the blind and visually impaired teens live far from each other, getting together is harder than it is with friends who live nearby. She is aware of the importance of friends.

*Getting ready for the future.* Much of Lisa's interview dealt with the activities in which she has chosen to be involved as a basis for her goals as an adult. Lisa is interested

in criminal justice and wants to be a lawyer. She chose public speaking activities and debate at school because she felt these would help her as a lawyer. She found a mentor to guide her in her learning specifically related to becoming a lawyer. As described above, Lisa recognized that she needed to learn what her sighted peers were doing, particularly regarding communication, and she chose to learn about body language and gestures and how to manage nonverbal communication because of that. This knowledge she feels is important in becoming a lawyer. She says,

I started out in public speaking because I knew I wanted to do debate when I got to high school. Because I knew that's something where you learn people skills and you learn how to argue, so that would definitely help me become a lawyer. But the prerequisite we had to take was public speaking, and the teacher of the debate and public speaking class is a lawyer. And so I told him that's what I wanted to do and he sort of guided me toward the classes and the things that I needed to become a lawyer.

Lisa is aware that her mobility in the community will affect her as an adult as well. She describes her orientation and mobility skills as good. Right now her mode of transportation is getting rides from her parents or friends. Public transportation in her town is not very extensive. However,

I've been on buses, I've been on city buses plenty of times going, at the school for the blind and then... we did a travelling course, like travelling around [city], we pretty much rode the city buses everywhere. And I rode the train once. So yeah,

I've been on public transportation...I would be able to plan a route in [city] for myself.

Currently, Lisa uses a long cane but eventually she would like to get a guide dog. ...people that travel with dogs seem to travel more efficiently but I don't really know. Many of the blind adults that I've met haven't had a cane. I've only met a few that had a cane and the other ones that had dogs seemed to travel really well with their dogs. So from what I've experienced, it's a positive way of, you know, being.

*Lisa summary.* An interesting part of Lisa's story is her perception of her differences from some other blind people she'd met and her desire to be like or unlike them. Lisa points out differences between herself and some other visually impaired people she's met, the ones she'd like to emulate and those she does not admire.

She finds it important and gratifying to be able to take part in social give and take. Having and being friends is part of her identity and she wants to be successful. Success for her entails a level of conformity, being independent, and being seen by others as competent.

For Lisa, social participation is an integral part of her developing identity and 'being.' She attaches importance to being able to talk with others, to having reciprocal relationships, and to being seen with positive regard. In addition, she experiences social participation as a challenge, as she describes herself as naturally shy and having to make

herself get out to be with other people. For Lisa, social participation is validation of being and preparation for later endeavors.

**Emerging Themes Overall.** Multiple themes emerged from analysis of each of the dyads and the two individual cases. These are summarized in Table 8 below.

Table 8.

*Case-by-case themes*

<u>Esther and Judy</u>	<u>Guillermo and Sam</u>	<u>Hal and Connie</u>	<u>Seth</u>	<u>Lisa</u>
<i>Self-direction</i>	<i>Just being able to go where I want</i>	<i>Seems the same but isn't</i>	<i>The need to know</i>	<i>Self-advocacy</i>
<i>Same ,just different family and self</i>	<i>Importance of sports</i>	<i>Getting around</i>	<i>Influence of friends</i>	<i>Importance of being social</i>
<i>Challenges of parenting</i>	<i>Protection and freedom to grow</i>	<i>Protection and freedom</i>	<i>I'm my own person</i>	<i>Getting ready for the future</i>
	<i>Like, but not like others</i>			

The primary issues addressed by the individual and dyadic themes were organized into overall themes for the study. The following themes emerged: “*Protection versus freedom,*” “*Concern about social participation,*” and “*Barriers and supports to social participation.*”

***Protection versus freedom.*** All parents described challenges in parenting and the underlying issue was the tension between wanting to protect their teen and knowing that

experiential freedom was necessary to their teen's well-being and growth. Parents described fears about allowing their teen to ride bikes (Sam), to go away to college (Connie, Judy, Sam) and generally to interact with others (Connie, Judy, Sam). Judy discusses the tension as an extension of the concerns any parent has. "So I think... she'll do OK. I mean it's scary for any parent." Connie captures the essence of this tension as she says, "... there's a lot of times that its best if I'm not around while he's learning things like this because I have a tendency for mother mode to take over and I recognize that so there's times I just need to walk away so I can let him get some experience it and let him really understand just how capable he is."

The teens all also addressed the issue of protection versus freedom but in a different way. The teens spoke to the freedoms they perceived their typically sighted had (especially with driving) in comparison to themselves, citing limitations imposed by the visual impairment rather than those imposed by parents. None of the teens spoke about being limited in their activities by parents. To the contrary, most spoke about being supported and even pushed by parents to participate in social activities.

An interesting variation on this theme of protection versus freedom emerged in the interactions between Esther and Judy. Judy tended to attribute negative events (Esther was bullied; Esther fell at a dance) to Esther's visual condition. Esther, however, did not see those events as related to her vision. She reported that the people who bullied her also bullied others who did not have visual impairments. She felt she was just one among many. She insisted that the fall at the dance "could have happened to anybody" and was

not due to her visual impairment. While her mother may see her in need of protection, Esther emphatically does not.

*Concern about social participation.* It makes sense that parents who chose to participate in a study about social participation have concerns about it. All parents interviewed discussed concerns that their teen was not engaging socially as much as or in the ways that the parents would like. Connie said directly, "...he doesn't socialize as much as I would like him to." And "...there are a lot of times that he just sits at home...he tends to do stuff with us and I'd like to see him going out with the kids and everything but I don't know." Sam said, (regarding the cosmetic effects of his son's visual condition) "He won't look at you in your eye... I think he developed not being very sociable because of that." Judy says, "...when we're in a social situation with new people, I think she gets a little shy because she can't necessarily see them or identify somebody from far away, even if it's someone she knows -- or she'll sometimes think it's someone and it's not and I think that makes her a little uncomfortable."

Two of the parents discussed concerns about social participation relating to their teens' dating. Both parents expressed that although they were pleased with their teens' interest in dating, they did not feel the dating behavior was typical. The dating seemed to have a peripheral, or in name only quality. Only one teen participant discussed dating. He presented his dating as something typical and expected. Three of the teen participants had not yet dated and did not discuss the issue.

The teen participants discussed barriers to social participation as well as frustrations encountered, but none explicitly stated concern about their own social participation. In contrast to their parents, the teens considered their social activities very much like their typically sighted peers’.

*Barriers and supports to social participation.* This could be considered an a priori theme as interview questions explicitly asked participants to address supports and barriers. Barriers broadly identified were lack of access to information and mobility. The majority of participants, parents and adolescents, identified lack of access to information as a barrier to social participation. Lack of access to information encompassed lack of classroom accommodations, and feelings related to needing and using accommodations. Mobility was another barrier identified. Supports included specialized vision-related services and team activities.

*Barriers: Lack of access to information.* Two participants experienced general education teachers who made functioning in classes difficult by failing to provide information in accessible formats or failing to interact with the vision teacher in a timely manner to provide needed adapted materials. One participant identified others’ use of nonverbal communication as a barrier to full participation and discussed needing to ask adults to use verbal forms of communication.

Two of the adolescents in dyads identified embarrassment at requiring adaptation and accommodation as barriers. This is included in this section as it relates closely to access to information. Guillermo expressed dislike of standing out when using large print

or other accommodations. Esther expressed feeling embarrassed about using her white cane, as she uses it intermittently and only in unfamiliar areas and has been accused by peers of faking her visual impairment. Esther, during her member checking visit, stated that she had missed assignment deadlines because she didn't want to get close to the chalkboard to see the instructions. In this case, the information was available and accessible but Esther didn't want to use the adaptation offered (moving close).

*Barriers: Mobility.* All participants identified mobility as a barrier in some form. Although all but one of the adolescent participants described themselves during interviews as good at O&M (an additional participant later said during member checking that street crossing scared her), all had received O&M instruction and several had received instruction in use of public transportation, all relied primarily on their parents for transportation in the community. All expressed that this reliance, while it allowed participation, was also limiting. Mobility issues also determined with whom the adolescent participants spent time. Most said that although their friends were mixed groups of typically sighted and visually impaired, they spent most time with their typically sighted friends because the others lived too far away to easily meet. The inability to drive was identified as a mobility problem by some of the participants. None of the participants could drive at the time of their interviews and each mentioned not driving or needing to rely on parents or others for rides as a social barrier. Most saw inability to drive as lack of freedom and did not identify alternatives to gain equal freedom to their typically sighted peers.



*Supports: Vision-related specialized services.* Supports identified primarily included specialized services, either school-based or agency-based, organized team, and group activities. Physicians and therapists were not identified as supports. The participants identified parents, agencies, and specialized school service personnel as supports to social participation. One identified a consumer organization as a support. Parents and family were identified most often as supports among the adolescents. Each participant received services from a vision teacher from the time they entered school. Most identified the vision teacher as an advocate for them. In a different way, agencies such as DARS and the regional Education Service Center were identified as supports. All participants recognized that they participated in many activities sponsored by these agencies and that these events offered most opportunities to socialize with visually impaired peers. Seth stated in his second interview that he met most of his friends for his favorite social activities through the Texas School for the Blind and Visually Impaired (his computer gaming friends) and goalball (sponsored by Regional Education Service Center).

All participants identified the vision teacher as their primary source of support for participation at school. Parents tended to rely on the vision teacher for advice regarding class sequences, additional needed services, community resources and advocacy. Adolescent participants recognized the assistance and support of their vision teachers as well. In contrast to the parents and perhaps as an indicator of the seamless provision of

services, the teens seemed to assume that the help would be available as needed. The adolescents saw their vision teachers as allies and advocates.

*Supports: Importance of team activities.* The importance of teams was identified by all three parents and all adolescent participants as well. All the participants placed a high importance on team activities whether this included goalball specifically or other team events such as debate. Most identified teams as the place they found belonging and friends and as a way of having things in common with others as a starting point for friendships. For example, Guillermo discussed rugby and bike riding as ways he became engaged socially. Esther and Seth also identified their participation in goalball teams as important supports to their social participation

Some participants viewed team involvement as a way to develop needed skills for the future or to assist with future plans. Hal discussed using extracurricular activities as a means of impressing college administrators. Lisa reported choosing to become involved with debate in order to learn skills she would need as a lawyer.

Parents identified team activities as important for providing opportunities for true reciprocal interactions, a sense of belonging, and a way of bringing the family together around a teen's activity. Guillermo's father, for instance said, "...this has boosted his confidence big time." And,

Developing...a type of camaraderie amongst the guys, you know? ... That he did not have...He feels part of something, of a group, and he knows that when he's out there playing that his teammates are counting on him.

Connie stated, "...he switched around his schedule, and everything so he could do that [debate]...and I was actually encouraged with that because that actually meant he made a connection with a group of people, you know?" Esther's mother, Judy, said,

... goalball is for us what soccer is for other families. Or baseball, they have this you know, team, that they do the same thing you know, they have their...so goalball for us is nice to be able to rally around something that she is doing and we're involved with it because she's helping coach.

The participants discussed multiple issues and shared a variety of personal experiences to illustrate their points. The overall emergent themes identified are "Protection versus freedom," "Concern about social participation," and "Barriers and supports to social participation."

## CHAPTER V

### DISCUSSION

This research explored the meaning of social participation to the study participants as well as their experiences of barriers and supports. The adolescents' responses were considered in relation to parent responses as well as to the Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences of Activities for Children (PAC) data. The findings of this research are presented in terms of their relation to the research questions.

#### **Social Participation Patterns and Meaning: Research Questions**

**Question 1: What differences exist in patterns of participation between typically sighted and visually impaired adolescents as measured by the CAPE and PAC?**

CAPE and PAC scores were not significantly different between the group of adolescents with visual impairment and the group with typical vision. Overall *With Whom* scores tended to be higher within the group with visual impairments and Activity Type –*Recreation*, *Where* scores tended to be higher among the typically sighted participants, although these differences were not statistically significant. In addition, although between group differences in Domain scores did not achieve statistical significance, participants with visual impairment reported more participation than the typically sighted participants in formal than informal activities. The higher scores on the

Overall *With Whom* scale and lower scores on the *Where* scale for Recreational Activity for the group with visual impairment is explained by the nature of the activities in which this particular group of adolescents reported participating. Many of the reported activities were sports and other events organized by state agencies or regional education service centers specifically developed for people with visual impairment. As these activities drew from statewide or regional populations, and as visual impairment is a low incidence disability, it makes sense that the group reported participation in activities with wider range of friends and acquaintances even when events took place close to the participants' homes. Since these activities were regional or local, the group participants were able to stay within their own communities. This is supported by data obtained from interviews in which all participants indicated that they socialize less with their visually impaired peers as they tend to live further away than their sighted peers and typically socialize with them at specialized programs and events. Greater participation in formal over informal activities by the participants with visual impairments similarly can be explained by the purpose of the activities sponsored by state agencies and education service centers. These agencies often schedule formal activities centered on adapted skills related to visual impairment and therefore are varied as well as highly structured as they are meant for skill-building.

**Question 2. What meaning does social participation have for visually impaired adolescents?**

Visually impaired adolescents are not a monolithic group and the meaning of social participation varies. On the surface, using information explicitly stated, social participation represents the opportunity to be viewed as capable, to develop identity, to gain freedom from parents, to reach personal goals, and to make choices. These elements together comprise self-determination as defined in the Expanded Core Curriculum; however, the meaning of social participation for these teens cannot be reduced to self-determination alone.

Each participant tacitly discussed social recognition as part of the importance of social participation. For instance, Guillermo wants to play rugby or football because his peers do; athletics is the way his friends achieve social recognition. Lisa and Hal do the same with debate team. Esther participates in volunteerism, an activity deemed of high importance by her religion and so, her religious peers. Activity itself is important, but in a different way than when one's engagement in it is recognized by others. This group of teens engaged in activities that provided social recognition and gave them a chance to be seen in a positive way. Lisa discussed being in situations in which peers talk around her rather than directly to her. Social participation means not being invisible.

Three of the participants stated they felt that the social activities in which they are currently involved may help them reach career goals. Esther wants to be a writer and believes that her social experiences will serve as a background for her stories and make

the stories more meaningful to others. Lisa has deliberately built a social activity agenda (debate team, mock trial) that will help prepare her for her chosen career as a lawyer.

Seth notes that it was through friends that he found his love of gaming and coding, which he now wants to be his career. Hal and Guillermo do not directly articulate ways in which social activities may influence them.

By nature of being adolescents, the members of this group of teens are still defining themselves. For each participant, the meaning of social participation will likely change over time. The stories they choose to tell about themselves and their experiences will probably change.

**Question 3. How do visually impaired adolescents experience supports and barriers to social participation?**

Each participant identified parents, vision teacher, and state agency as supports. Interestingly, only one participant identified friends as a support (Seth said it was friends who involved and supported coding and gaming). None question the existence of these supports to their participation and they all generally take it as given.

Perceptions and experiences of barriers were more diverse although commonalities existed. Three of the participants described barriers created by school personnel: classroom teachers who refused to provide accommodations needed for their participation. One participant chose to address barriers she encountered directly. A member of the school debate team, she found the need to ask the adult officials involved to use verbal rather than their traditional gestural signals so that she would be able to

fully participate. She doesn't question why the adults did not offer this or notice it as problem; she rather assumed the problem was hers to solve. She stated that barriers are an expected part of being blind. Only one participant reported barriers in the form of bullying and she felt that this was unrelated to her vision impairment. She was careful to point out that other students, without any type of impairment, were bullied as well. More subtle forms of barriers were reported by other participants – parties heard about after the fact, with no invitation; difficulty attending a school dance because of the lighting; sighted people seeming uncomfortable around the teen who was visually impaired or blind and so ignoring the person; being overly solicitous or in one case; accusing the teen of faking her vision problem.

Mobility was identified by all participants, either directly or indirectly, as a barrier to social participation. Interestingly only two directly stated they resented the ease and freedom they perceived their typically sighted peers have. Four stated that not driving affects them socially. One participant reported using biking as a form of independent mobility. One specifically identified mobility issues as, “embarrassing when you have to rely on your parents for transportation” (stated during member-check conversation). Another participant who expressed resentment of her peers' freedom in driving said she did not want to arrange rides with her driving friends as none had been driving very long and so she didn't feel safe with them driving yet. Of note, all participants had received Orientation and Mobility (O&M) services as a related service through school for most of their school careers. Two reported attending specialized programs that specifically



addressed O&M and use of public transportation. Four of the five describe themselves and are described by parents as good at O&M. Yet all reported that they did not actually use public transportation in their daily lives and instead were dependent on parents or relied on friends.

Access to information was identified by all of the participants as a barrier. Hal's description of being denied reasonable accommodation in his AP math class is the strongest example of this. Esther also had difficulty obtaining information in her math class in a form she could access. Esther and Guillermo identified feeling embarrassed by their differences in accessing information necessitated by their vision function.

Guillermo reported that he felt embarrassed, when he was younger, to have to sit at the front of the class and to use large print. He sees his feelings as something to overcome. Esther, in her member check visit, also described feeling embarrassed to move close to the chalkboard before the end of class to check on assignment deadlines and requirements; she has consequently missed assignments because she didn't know about them. Interestingly, although Lisa also identified the same type of barrier (lack of knowledge about her and others' body language, difficulty getting class information in a format compatible with her screen reader software), she chose to address the issues directly rather than avoiding them. She took initiative to ask for a mentor to help with learning about body language and she found alternatives to the incompatible format.

**Question 4. How do qualitative data regarding adolescents with visual impairments' experiences of social participation compare with the findings of the CAPE and PAC?**

The emerging themes derived from the interviews (group information) are not reflected in test scores as they are not addressed by either CAPE or PAC. Individuals' scores compared to individual interviews support each other in general. However, some discrepancies were found between scores and interview data. In Esther's case, CAPE scores indicated that her lowest level of enjoyment was with self-improvement activities. However in interviews (both initial and member check), Esther indicated she most enjoyed self-improvement activities. She verified the interviewer's hypothesis that the discrepancy between test and interview data was due to choosing activities that present a challenge. Therefore, at a given moment Esther may not thoroughly enjoy the self-improvement activity, but overall she states she loves trying new things and challenging herself. Guillermo's CAPE scores were consistent with his interview statements. One small discrepancy was found in his PAC scores. Guillermo's PAC scores indicated a slight preference for informal activities while his interview data indicate a preference for formal activity such as sports. Hal's, Seth's and Lisa's CAPE scores are strongly consistent with their interview data.

**Question 5. What is the meaning to parents of their visually impaired adolescents' social participation?**

Parents tended to describe social participation as a step toward independence. Esther's mother, for instance, described Esther's current interests as abilities as laying groundwork for a career. Hal's mother also sees social participation as a path to independence and future successes. She described understanding the need to allow her son to experience a variety of social activities in order to learn how to deal with them. Additionally, each parent described social participation as presenting a conflict for them between wanting to protect their child from possible negative social encounters and simultaneously understanding that their child needed to have experiences on their own in order to develop to their potential. Esther's mother also spoke to the conflict, "I think we just are always trying to do things that are somewhat family oriented but also when the opportunities arise and she's going to go on her own, we try to support that too." She is concerned about Esther's social involvement and tries to provide as many opportunities as possible. The meaning of social participation to the parents of the adolescents included in this study involves an acknowledgement of limitations as well as the ability to make room for possibilities. The parents see social experiences and participation now as laying the foundation for adult life.

**Question 6. How do parents perceptions of social participation differ from the perceptions of adolescents?**

In contrast to each adolescent describing him- or herself as basically social or shy but social and describing him- or herself as having friends, all three parent participants expressed concern about the level of their adolescent's level social participation. Hal's mother, for instance, acknowledged that he is involved in a variety of activities but stated "...he doesn't socialize as much as I would like him to." She feels he only recently found genuine connections with his peers. Even regarding dating, she relates stories about peripheral girlfriends (one who told people she was dating Hal but refused to go places with him, and one who Hal felt she wanted to be just friends) and states she is not sure if they do the things other boyfriends and girlfriends do. Of note, although Hal's mother discussed Hal's dating, Hal himself did not share that he had a girlfriend. Guillermo's father, too, says of his son's relationship with his girlfriend, "...they don't have a relationship like your typical... relationship where high schoolers would have." He also states that he thinks Guillermo does not have close friends. Esther's mother doesn't discuss dating (Esther is not yet dating) but does say she thinks Esther is little shy in crowds or large gatherings as she may not be able to identify familiar people. She does state that Esther has some long term close friends.

All parents directly discussed the importance of their children feeling a part of something and bonding with others. Team activities were identified as important, with Guillermo's father and Esther's mother identifying sports teams as providing this

experience and Hal's mother identifying debate team. The adolescents did identify teams as important but not all identified a sense of belonging as the primary importance. Lisa, for example, stated she is on the debate team because she feels it will help her prepare for her chosen career path as an attorney and in fact described difficulties associated with being on the team from resentment by others that she was chosen. Guillermo did identify sports as important to his belonging to a group and having things in common with others. Esther and Hal said that goalball specifically was a place for spending time with their friends who were visually impaired.

Parents tended to separate barriers imposed by the visual impairment from those caused by external factors and they tended to express stronger reactions to external barriers to social participation than those of their adolescents. Guillermo's father stated he felt that his son lacked confidence because of the appearance of his eyes (and subsequent questions from others). He also expressed dismay at the limitations Guillermo's visual impairment imposed. Hal's mother expressed frustration and anger in describing a school-based barrier: Hal had an AP math teacher who refused to make accommodations for him. Esther's mother expressed concern about bullying and about lack of accommodation in a math class. Guillermo's father discussed frustration and sadness at the phenomenon of typically sighted peers finding interest in activities in which his son could not participate, causing them to drop him as a friend. In general, the existence of barriers seemed to encourage the parents to become advocates for their children's participation and for accommodations to be made.

In contrast, the teen participants tended to view social barriers as a given, and some identified the accommodations and adaptations they needed as barriers to participation. Guillermo, for instance, discussed initial embarrassment at needing to use large print and sit near the front of his class as these things made him stand out. Esther, during her member check visit, said that she had missed deadlines for some assignments this year as she did not go close to the board to read them. She accepted her responsibility in failing to meet the deadline as the information was available to her but she did not wish to stand out by moving close to the board. Lisa and Guillermo, however, also saw barriers as a given, “I mean, like, that’s just pretty much everything being blind or visually impaired,” and as problems to solve. Both expressed, as Esther did, in different ways, that it their responsibility to overcome barriers. For instance, Lisa asked a teacher/coach for assistance in learning body language so she could compete at the same level as her peers and she directly asked adult judges to speak rather than use gestures for communication.

Two of the participants did express resentment at the barriers imposed by their visual impairment. Hal confessed that he felt a little jealous of his friends whom he saw as having fewer barriers. Esther, also, during a member checking session, expressed a bit of resentment regarding her perceived limitations on her freedom compared to her typically sighted peers. However, the majority of the teens’ responses seemed to indicate an acceptance of barriers as part of life in contrast to the parents’ responses indicating

sadness and anger at the barriers encountered a view of barriers as something to fight against as opposed to their children's view of barriers as problems to solve.

### **Social Participation of Adolescents with Visual Impairment**

The themes that emerged from this study are consistent with the areas identified in traditional blindness/visual impairment services literature and occupational therapy literature. Researchers have found that adolescents who are visually impaired, compared to their typically sighted peers, have slightly smaller circles of friends, participate in a narrower range of and more passive activities, tend not to find their own first jobs (teachers, counselors, or caseworkers secure them), spend more time alone after school, may experience embarrassment on using needed adaptations, and may have more limited community mobility, which all affect social participation (McDonnell, 2010; Gold et al., 2012; Kef, 1997, Kroksmark & Nordell, 2001; Pinguart & Pfeiffer, 2013; Pinguart & Pfeiffer, 2011; Sacks & Wolffe, 1998; Sacks et al., 1992; Wolffe & Sacks, 1997; Wolffe, 2006a; Wolffe, 2006b). Salminen and Karhula (2014) investigated challenges to social participation of 14 young people with visual impairment between 16 and 22. They used the Canadian Occupational Performance Measure (COPM) with the participants to identify the youths' perceptions of their challenges; they also used interviews with the participants and their parents to identify more in-depth data. Their aim was to portray these challenges in terms of the International Classification of Functioning (ICF). Although they coded the challenges identified within ICF categories (for instance, interpersonal interactions and relationships, domestic life, major life areas), the

challenges found were similar to those found in research discussed previously: mobility, meeting friends, recreation and leisure skills, and feelings of embarrassment about using assistive devices. The researchers found that the environments in which participants lived could be considered barriers or facilitators of social participation. Similar to Salminen and Karhula (2014), the findings of this dissertation study found barriers to social participation include mobility (both skill and lack of transportation options), and lack of access to information (including embarrassment at using or reluctance to use adaptations or assistive devices).

The participants in this study reported participation with a slightly wider range of friends and acquaintances than their sighted peers. In contrast with previous research addressing social networks of adolescents who are visually impaired (Wolffe & Sacks, 1997; Rosenblum, 1997; Kef, 1997), the focus in this study was on diversity of social network as opposed to size. Previous research investigated numbers of close friends (Gold et al., 2010; Wolffe & Sacks, 1997; Rosenblum, 1997). This study, using the CAPE, explored *types* of others with whom activities took place (alone, with immediate family, with other relatives, with friends, with others such as multiple types of people who did not fit other categories). The difference in focus accounts for the apparent divergence of results of this study from those of previous studies, which indicate that the social networks of adolescents who are visually impaired are more limited than those of their typically sighted peers (Wolffe & Sacks, 1997; Rosenblum, 1997; Kef, 1997).



**Parent-child perspectives.** The adolescents in this study often described themselves and their experiences differently than their parents described them. All of the adolescent participants in this study described themselves as social even as they also identified themselves as shy, when asked during their interviews. In contrast, all parents expressed concern about their adolescents' social participation. This is consistent with Salminens and Karhula (2014) who found that adolescent participants in their study perceived their abilities as better than did their parents. It makes sense that the parents who chose to participate in a study about social participation might have concerns about social participation. Whiteneck and Dijkers (2009) suggest that people with disabilities who participate most are likely to notice more barriers to participation because they encounter them more than people who choose not to participate.

All adolescent participants discussed barriers they encountered in social participation, but most viewed the barriers as something either external or something that happened to everyone and was a problem for everyone else as well (teacher used non-verbal communication; anyone could slip and fall in the dark). Parents seemed to tend to view social participation barriers as occurring because their child was blind or visually impaired. This observation was not echoed in most other studies however. There is tension between parental desire to protect and shelter their children from harm and the knowledge that children's development and independence requires freedom to experience life situations. Salminen and Karhula (2014) found similar tension expressed by parents during their interviews. They discuss briefly the conflict parents expressed in letting go of

their maturing children. Parents struggled to find a balance between giving their children responsibilities and freedoms and giving them help.

### **Occupational Adaptation of Adolescents with Visual Impairment**

Occupational Adaptation (OA) explains the process of adaptation in terms of the interaction of the person (comprised of sensorimotor, cognitive, and, and emotional elements) with his or her environment (DeGrace, 2007; Hamilton, 2001; Schkade & McClung 2001; Schkade & Schultz, 1992). The person is understood as having an innate desire for mastery and the occupational environment presents a demand for mastery in the form of occupational challenges. Interaction of the person with the environment creates a press for mastery which results in an adaptation and adaptive response.

Adaptive response behaviors may be hyperstable, hypermobile, (highly variable, very active), or mature (modulated, goal directed, and solution oriented) (Schkade & McClung, 2001). The cases of Hal and Lisa offer examples of the different types of adaptive behaviors. Hal's involvement in multiple activities with only limited connection to others may be an example of a hypermobile adaptive response. He wants to have close friends and he responds by participating in many activities, without, per his mother, engaging with the people within the activities. He demonstrates a high level of activity and an interest in doing even more, but does not achieve his goal, which is development of reciprocal relationships. Lisa demonstrates a mature adaptive response when she recognizes the occupational of challenge of understanding nonverbal communication during debate meets and as a solution asks judges to communicate verbally. In contrast,

she describes behaviors that can be characterized as hyperstable, when discussing her previous social behavior and her initial choice to avoid contact with new people as she was nervous about her ability to interact. Lisa found that remaining alone (adaptive response to occupational challenge of talking with a new person at a social event) was not effective or efficient (did not meet her goal of making friends, used much energy with anxiety) and was not satisfying to herself or her parents. After her evaluation of her responses, she chose to change and to go to situations in which she would encounter new people. She states she can now encourage herself to try talking with new people (integration of adaptive response, increase in adaptive behavior repertoire, experience of relative mastery).

The therapist's role with an OA framework is facilitator, enabling conditions that promote the experience of relative mastery (an experience of effectiveness, efficiency, and satisfaction to self and others) (DeGrace, 2007; Hamilton, 2001; Shultz & Schkade, 1992) and can help determine ways to enable engagement (Schkade & Schultz, 1992). The identification of the client, rather than the therapist or others, as the agent of change makes OA particularly useful with the population of adolescents who are visually impaired as they move toward independence and self-determination. In addition, it seems to fit well with vision educators' emphases on developing skills for self-determination (Lewis & Wolffe, 2006; Cleveland et al., 2007) for students who are visually impaired. Self-determination is part of the Expanded Core Curriculum (Huebner et al., 2004) which

identifies adaptive skills that students with visual impairment need in addition to the typical core curricula provided through public school.

Use of an OA framework is one way the occupational therapist can contribute to the traditional team working with the adolescent who is visually impaired, by bringing a unique perspective. An important assumption of OA is that achievement of component skills, although necessary (occupational readiness), does not automatically lead to occupational adaptation. Hal, for example, possesses a wide variety of discrete social skills (his mother states that others view him as a leader, he has a good sense of humor, he can carry on a conversation and even debate well) but he does not typically engage or connect with others. While educators, including vision teachers and orientation and mobility specialists, focus on skill building (Sacks & Wolfe, 2006), in a sense promoting expertise in social skills, the occupational therapist will focus on promoting expertise in adaptation. Using the OA approach, the occupational therapist can collaborate with the vision teacher and certified orientation and mobility specialist to identify elements of the occupational environment (school) and role expectations and to foster effective adaptive responses. For instance, one teen with whom the investigator worked encountered an occupational environment in which she was expected to be helpless and socially awkward. When faced with the mobility task of negotiating a route from one classroom to another, she frequently got lost. She responded to getting lost with the same ineffective adaptive responses each time: she continued walking and cried or she stopped and waited for someone to help her. She described her experience as being “tied up” and unable to

think. Her adaptive gestalt was dominated by emotional psychosocial responses. The certified orientation and mobility specialist addressed the teen's need for specific skills related to use of her cane, directions, and landmarks. The vision teacher addressed skills for requesting assistance. The occupational therapist worked to bring the teen an awareness of her own adaptive gestalt so she could understand the interplay among the elements. The focus was on adding to the teen's repertoire of adaptive responses and in doing so increasing her sense of relative mastery. Through experience she learned she could allow her cognitive abilities to take a greater part in forming her adaptive responses. The teen identified that when she was lost she could take a breath, then review her landmarks and ask for assistance in finding one to re-orient herself, rather than allow her upset feelings to control her outcome. She used both the component skills taught by her vision teacher and certified orientation and mobility specialist and her understanding of the adaptive gestalt to initiate adaptations in new situations. As a result, she was more satisfied with her performance, used less primary energy in mobility, and was effective in meeting her goal of arriving at her destination independently.

### **Implications**

The findings from this study included parents' experience of struggle with wanting to protect their teens and their teens' need for freedom; parental concerns about their teens' social participation, including dating; and barriers and supports to social participation. Primary barriers to social participation identified include mobility and lack of access to information. All of these are areas appropriately addressed by occupational

therapists. Little attention, however, has been given by our profession to aspects of the occupation of social participation of children and adolescents with visual impairment and blindness, as evidenced by the small amount of research literature generated by the field. As a result, we do not yet have an occupational therapy knowledge or evidence base from which to determine when intervention is needed or how to effectively intervene in this area. The social participation needs of adolescents who have visual impairments are unique due to the inadequate or complete lack of visual information available to them for validation and learning. Therefore, a unique evidence base is needed.

With an adequate evidence base, occupational therapists could be valuable team members for adolescents who are visually impaired and their families. For instance, occupational therapists can collaborate with parents in finding strategies to navigate the transition of their teens to adulthood. The therapist can provide support for the parents when needed, as they work to release their adolescent from their protection to a life of full experiences. Identifying ways to support their adolescent in exploration of self-identity (including sexuality and dating), acquiring autonomy and exercising self-determination, and in general moving into adult life are all ways occupational therapists could contribute to the life of the adolescent with visual impairment and his or her family. These are all typical functions of the occupational therapist.

Though almost all the adolescent participants in this study described themselves as good at O& M and had received extensive O&M services through their school and other sources, they were all dependent on their parents for transportation. Community

mobility is within the domain of occupational therapy (AOTA, 2014) and is therefore appropriately addressed by therapist. There is no evidence base within current occupational therapy literature for addressing community mobility with visually impaired adolescents, however. It is not suggested that occupational therapists take on the role of Orientation and Mobility Specialists, whose role is to teach specific adapted skills for safe, effective and independent travel to clients (consumers) who are visually impaired. It is however important that occupational therapists become more aware of issues involved in independent travel for a child or adolescent who is visually impaired.

The identification of lack of access to information as a barrier to social participation also carries with it a need for establishment of an evidence base. Lack of access to information involves a wide area as it includes diverse issues such as understanding the physical features of the environment, social contexts and concepts, and knowledge and skill for using adaptations including technology to access information. The occupational therapist could have a role in all the areas involved. Assisting the adolescent in understanding the intangible social cues that ‘make or break’ an adolescent (trends in makeup, clothes, ways of moving, subtle forms of flirting, among others, described by Wolffe (2006b)), addressing spatial orientation, and assisting with developing self-advocacy abilities for access to information are all ways in which occupational therapists could appropriately contribute.

## **Limitations**

Several limitations are noted for this study. The sample size was small for the quantitative portion of the study (Part One) although saturation was reached for the qualitative portions (Parts Two and Three). The participants included two siblings and their parents did not participate in the interviews. The participants self-selected; they volunteered after hearing about the research through investigator presentations, social media, and word of mouth. Most of the participants were recruited at goalball games or other state services organized social events. Therefore, the participants' responses are not representative of the experiences or attitudes of the entire population of adolescents who have visual impairments and results may be biased. Neither does the participant group represent the spectrum of visual impairment in the general population. The research group consisted of two totally blind siblings, one teen who was functionally blind, and two teens with vision that was good enough for large print or standard print reading. All participants were severely visually impaired from birth, with the exception of one who lost his vision at age five.

## **Future Research**

Because of the small number of participants and the bias toward participation created by the recruitment process (most were recruited from organized social activity programs), the findings are applicable only to the participants and cannot be generalized. In addition, the levels of the participants' vision were not representative of the population of visually impaired individuals, as the study participants comprised a majority of blind



individuals, which contrasts with the population of school-aged individuals in Texas of whom only 20-30% are considered functionally blind (K. Wolffe, personal communication 3/21/16).

The information that emerged from this study is useful as a starting point for future research for occupational therapy. Research needs to determine motivators for development of social competence for these young people and identify and develop appropriate interventions. Specific attention to challenges to social participation identified in this study and previous research is also needed. Areas of need include: ways of increasing safe and independent community mobility; accessing social and other information essential to successful social participation; providing supports for families to anticipate and manage transitions; and accessing resources.

## **Conclusion**

This study explored the social participation issues of adolescents who are visually impaired and their families. Several challenges to social participation were identified by participants and these were similar to challenges identified in previous research. The need to build an evidence base for intervention with this population is apparent. Although not immediately generalizable to the larger population of individuals who are blind or visually impaired, the information learned from these participants does add to the occupational therapy knowledge and evidence base about the social experiences of visually impaired young people and their families.

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APPENDIX A  
Institutional Review Board Approval Letters and Extensions



**The Graduate School**

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0028311

November 7, 2013

Jessica Lampert  
7706 Meadow Road, #125  
Dallas, TX 75230

Dear Ms. Lampert:

I have received and approved the prospectus entitled *Social Participation: Perspectives on the Lived Experiences of Adolescents Who have Visual Impairments* for your Dissertation research project.

Best wishes to you in the research and writing of your project.

Sincerely yours,

A handwritten signature in blue ink that reads "Ruth A. Johnson". The signature is written in a cursive style and is positioned above the typed name and title.

Ruth A. Johnson, Ph.D.  
Associate Dean of the Graduate School

kjb

cc: Dr. Catherine Candler, Director, Occupational Therapy



Institutional Review Board  
Office of Research and Sponsored Programs  
P.O. Box 425619, Denton, TX 76204-5619  
940-898-3378  
email: IRB@twu.edu  
<http://www.twu.edu/irb.html>

DATE: October 17, 2014  
TO: Ms. Jessica Lampert  
School of Occupational Therapy - Dallas  
FROM: Institutional Review Board - Dallas

Re: *Extension for Social Participation: Perspectives on the Lived Experience of Adolescents Who Have Visual Impairments (Protocol #: 17483)*

The request for an extension of your IRB approval for the above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. If subject recruitment is on-going, a copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

This extension is valid one year from October 14, 2014. Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Noralyn Pickens, School of Occupational Therapy - Dallas  
Dr. Catherine Candler, School of Occupational Therapy - Dallas  
Graduate School





Institutional Review Board  
Office of Research and Sponsored Programs  
P.O. Box 425619, Denton, TX 76204-5619  
940-898-3378  
email: IRB@twu.edu  
<http://www.twu.edu/irb.html>

DATE: September 30, 2015

TO: Ms. Jessica Lampert  
Occupational Therapy - Dallas

FROM: Institutional Review Board - Dallas

Re: *Extension for Social Participation: Perspectives on the Lived Experience of Adolescents Who Have Visual Impairments (Protocol #: 17483)*

The request for an extension of your IRB approval for the above referenced study has been reviewed by the TWU Institutional Review Board (IRB) and appears to meet our requirements for the protection of individuals' rights.

If applicable, agency approval letters must be submitted to the IRB upon receipt PRIOR to any data collection at that agency. If subject recruitment is on-going, a copy of the approved consent form with the IRB approval stamp is enclosed. Please use the consent form with the most recent approval date stamp when obtaining consent from your participants. A copy of the signed consent forms must be submitted with the request to close the study file at the completion of the study.

This extension is valid one year from October 14, 2015. Any modifications to this study must be submitted for review to the IRB using the Modification Request Form. Additionally, the IRB must be notified immediately of any unanticipated incidents. All forms are located on the IRB website. If you have any questions, please contact the TWU IRB.

cc. Dr. Noralyn Davel Pickens, Occupational Therapy - Dallas  
Graduate School

APPENDIX B  
Agency Letters of Agreement



Debra Wanser  
Commissioner

March 25, 2013

To Whom It May Concern:

This letter is in recognition that OARS Division for Blind Services and Ms. Jessica Lampert are working together to develop a partnership that will benefit individuals who are disabled. Ms. Lampert has expressed an interest in recruiting our consumers who are blind or visually impaired for research in a study titled *Social Participation: Perspectives on the Lived Experience of Adolescents Who Have Visual Impairments*. We are excited about this opportunity and will send the information to consumers for them to determine if they would like to participate in this research study.

If you have any questions or need additional information, please contact me at 214-378-2640.

Sincerely,

Rolinda R. Duran  
Field Director – Dallas Region

*Partnerships for Independence*

Division for Blind Services, Dallas Field Headquarters, 6500 Greenville Avenue, Suite  
250, Dallas, TX 75206  
214-378-2600, 1-800-687-7017, fax 214-378-2631

**AFB** American Foundation •  
for the Blind

Expanding possibilities for people with vision loss

AFB Center on Vision Loss    Tel 214.352.7222  
11030 Abies Lane        Fax 214.352.3214  
Dallas, TX 75229        www.afb.org

May 14, 2013

Jessica Lampert, OTR, COMS, CLVT  
7706 Meadow Rd #125  
Dallas, Texas 75230

Dear Jessica,

The American Foundation for the Blind Center on Vision Loss will be glad to assist you in your efforts to recruit teenagers and their families for your research. We will place a flyer in information bags given to visitors as well as sending announcements via email to our extensive contact list which includes Teachers of the Visually Impaired as well as many consumers and families who have visited the Center.

Sincerely,

Neva Fairchild  
National Independent Living Associate  
American Foundation for the Blind (AFB)  
Center on Vision Loss  
11030 Abies Lane  
Dallas, TX 75229

---

*Incorporated in 1921*

## Your AERNet request

Friday, April 5, 2013 2:19 PM  
From: "Ginger Croce" <ginger@aerbvi.org>  
To: jlampert@att.net  
Cc: "Barbara James" <barb@aerbvi.org>

Hi Jessica,

Thanks so much for asking about posting something on the listservs...many people post the info about studies without inquiring about our policy.

The practice has been that we request that people consider renting the AER member list since that goes out to a wide cross section of individuals who might be good candidates for studies. Also, the board has had several discussions about using the member list for non-AER purposes.

There is no policy per se against members posting the request, but we do ask that if the organization/person doing the study does post something on an AER listservs but does not rent the list, that they agree to share the study results as a benefit to AER members, usually through a summary in AER Report.

I've attached the list rental information for you just in case your organization can support you.

Thanks for your inquiry.

Ginger Croce

Ginger Croce

Senior Director of Marketing & Operations

Association for Education and Rehabilitation of the Blind and Visually Impaired

1703 N. Beauregard St., Suite 440

Alexandria, VA 22311-1744 USA

(703) 671-4500, ext. 203

Toll Free (877) 492-2708, FAX (703) 671-6391

[ginger@aerbvi.org](mailto:ginger@aerbvi.org), [www.aerbvi.org](http://www.aerbvi.org)

APPENDIX C  
Interview Guides

## Interview Guide - Adolescent

This interview is part of a research project that I'm doing as a requirement for my Ph.D. program. Thanks for agreeing to be part of it. This interview is all about social participation- the things you do with other people, anywhere. I want to ask you a few questions. Remember we can stop for a break or even for good any time. Just let me know.

1. Tell me about your relationships with your friends and family.

Prompts: What is your parents' view of you as a person? For instance, do they see you as independent, outgoing, shy, active, a loner, social?

How do your friends see you?

Are your friends a mixed group –sighted and visually impaired- or more one or the other? What brought that about?

2. Tell me about the things you enjoy doing with your friends and family.

Prompts: How are your activities with friends or family like and different from those of kids your age who are sighted?

What's important to you to be able to do?

What makes those things important?

How do you get to your activities outside your home?

3. What types of responsibilities do you have at home? How do they compare to those of your friends without vision conditions?

Prompts: Which home responsibilities have you discussed with your friends?

What chores do you do?

4. Many kids your age have fun with some type of volunteer work/community service or hold part-time or summer jobs to earn extra money. What is your experience with these activities?

Prompts: Have you ever volunteered or done community service? Tell me about it.

How did you choose what to do?

Have you ever worked for pay? Tell me about it.

Have you made any friends at your volunteer or paid jobs?

5. What kinds of things would you like to do in your life?

Prompt: What makes those things important?

6. How do you think your social activities with others now will influence your choices (activities, partners, friends) following graduation?

Prompts: How will your experiences help you? How will your experiences make things difficult?

7. What suggestions do you have for teachers, counselors, therapists and parents about helping kids who have visual impairments with social activities?



## Interview Guide - Parent

Thank you for agreeing to participate in this study. This interview is part of a study I'm undertaking as a requirement for my Ph.D. program at TWU. The interview is about your perceptions and experiences of your child's social participation. I'm going to ask you to share with me some of your thoughts and feelings. Please remember, we can stop any time for a rest and you can discontinue the interview at any time. If you're ready, let's start.

1. How do you view (child's name)? For instance, is s/he independent, outgoing, shy, active, reserved, social, able to things other kids can do?

Prompts: Are (child's name) friends a mixed group –sighted and visually impaired- or more one or the other? What do you believe brought that about?

2. Tell me about the way your child uses his/her time.

Prompt: What kinds of things does (child's name) do at home, at school, or in the community with other people?

3. How are (child's name) activities like those of kids his/her age who are sighted? How are they different?

Prompts: What barriers does your child face in social activities?

What supports your child's social participation?

Tell me about social activities your child has attended that were sponsored by the school district vision program or by an agency like DARS.

Tell me about social activities your child has attended that were not organized by an agency or school.

4. How does (child's name) get to his or her social activities?

Prompts: Does he/she want to go to events and activities independently? Do you allow this? Does your child arrange his/her own rides?

5. What does your child do that helps others or him- or herself and how do these activities help or hinder social engagement?

Prompts: What chores does he/she do?

How does he/she pick out clothes/manage hair/shave/cook?

Has she ever volunteered in the community? If not, and he/she wanted to, what got in the way? If yes, how was the volunteer activity chosen?

6. Many teens your child's age have had part-time or odd jobs. Has yours wanted one? Has he/she ever worked for pay? How has this helped or hindered his/her social engagement?

Prompt: What challenges does your child face with working for pay?

7. What kinds of things would you like to see (child's name) do in his/her life?

Prompt: What makes those things important?

8. How do you think your child's social participation now will affect his/her plans and choices for the future (activities, friends, partners)?

Prompt: How will his/her experiences help? How will his/her experiences make things difficult?

9. What suggestions do you have for teachers, other professionals and parents about helping adolescents who have visual impairments socially move into adulthood?

APPENDIX D  
Consent Forms

**Texas Woman's University  
Consent to Participate in Research  
Participation in Study 1**

Title: Lived Experience of social participation patterns: Visually impaired adolescents and their parents

Investigator: Jessica Lampert, MA  
Telephone: (214)205-9023 E-mail: [jlampert@att.net](mailto:jlampert@att.net)

Advisor: Catherine Candler, PhD  
Telephone: (214)706-2350 E-mail: [ccandler@twu.edu](mailto:ccandler@twu.edu)

Explanation and Purpose of the Research

Your child is invited to take part in a research study. The study is part of Ms. Lampert's degree requirements at Texas Woman's University. One goal of this study is to learn more about the social participation of visually impaired teens. Another goal is to compare the activities of visually impaired teens to those of sighted teens.

Research Procedures

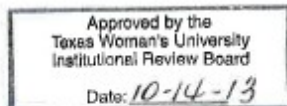
In this study, Ms. Lampert will ask your child questions about what he or she does during the day. Questions will center on type of activities your child does, how often, with whom and where the activity is done and how much the activity is enjoyed. A formal assessment protocol will be used. If you would like to see the questions that will be used, please ask Ms. Lampert to provide a copy of the assessment. The total time needed for this study is expected to be about 1 hour.

Your permission is needed so that the researcher may interview your child for the study. Any person's participation in this study is purely voluntary. A statement of agreement to participate will be obtained from your adolescent if you give permission.

Potential Risks

Potential risks related to your child's participation include possible fatigue or anxiety. Your child may take breaks during the interview as needed. If your child experiences discomfort at any time, your child may stop the interview.

Another possible risk as a result of your child's participation in this study is release of confidential information. There is a potential risk of loss of confidentiality in all e-mail, downloading, and internet transactions.



\_\_\_\_\_Initials

We will minimize these risks in the following ways: A code, rather than your child's real name, will be used on the survey/assessment papers. Hard copies of the survey completed will be stored in a locked filing cabinet on the TWU campus. If identifiable information is stored in electronic form, a password protected flash drive and/or computer device will be used. Information stored on computer hard drive will identify participants by code. The master list containing the participants' names matched to their codes will be kept in a separate locked file cabinet on the TWU campus. Identifiable information will be destroyed within 3 years of completion of the study. Hard copy identifiable data will be destroyed by shredding and disposal of shredded paper in trash system. Identifiable electronic data will be destroyed by deletion of information from drive. It is anticipated that the results of this study may be published in research publications. No real names or other identifying information will be used in any publication. **Confidentiality will be protected to the extent that it is allowed by law.**

An additional risk of participation in this study is the experience of feeling coerced to participate. To minimize the risk of coercion, we will take the following steps:

1. The principle investigator will not be professionally affiliated with the agency from which participants are recruited
2. We will not recruit participants from among the individuals or families who have been served by the principle investigator within the last 6 months.
3. You are informed that your decision to participate or decline participation will not affect the services your child receives through any agency or individual from which you may have received recruitment information.
4. You may decline participation in the study simply by not contacting the principal investigator or by indicating now or at any time that you do not want to participate.

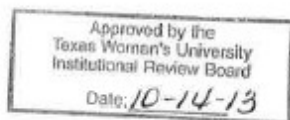
The researchers will try to prevent any problem that could occur because of this research. You should let the researchers know immediately if there is a problem and they will help you. TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

#### Participation and Benefits

Your child's involvement in this research study is completely voluntary. You or your child may discontinue your child's participation at any time without penalty. There are no direct benefits of participation in this study. You will receive a summary of the results of the study upon its completion if you request it. \*

#### Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).



\_\_\_\_\_ Initials

Consent for Participation (Study 1)

When you sign this form, **you are giving permission for your child to participate in this research.** You may revoke or cancel your permission and withdraw from this study at any time while the study is being carried out by contacting the researchers.

\_\_\_\_\_  
Signature of Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Child's name

Minor's Assent Statement (Study 1)

I want to participate in this research. I understand that I will be interviewed and asked to talk about the activities I do with other people and how I feel about them. I will need to meet with Ms. Lampert 1 time for about an hour. I understand that I can change my mind about participating at any time and for any reason without consequences.

\_\_\_\_\_  
Child's Signature of Assent

\* If you would like to receive a summary of the results of this study, please provide an address to which it may be sent:

\_\_\_\_\_

\_\_\_\_\_  
(Initials)

Approved by the  
Texas Woman's University  
Institutional Review Board  
Date: 10-14-13

**Texas Woman's University  
Consent to Participate in Research  
Participation in Study 2**

Title: Lived Experience of social participation patterns: Visually impaired adolescents and their parents

Investigator: Jessica Lampert, MA  
Telephone: (214)205-9023 E-mail: [jlampert@att.net](mailto:jlampert@att.net)  
Advisor: Catherine Candler, PhD  
Telephone: (214)706-2350 E-mail: [ccandler@twu.edu](mailto:ccandler@twu.edu)

Explanation and Purpose of the Research

Your child is invited to take part in a research study. The study is part of Ms. Lampert's degree requirements at Texas Woman's University. One goal of this study is to learn more about the social participation of visually impaired teens. Another goal is to compare the activities of visually impaired teens to those of sighted teens.

Research Procedures

In this study, Ms. Lampert will ask your child questions about what he or she does during the day. An interview with open-ended questions will be used. If you would like to see the base questions your child will be asked, please let Ms. Lampert know. Because this interview is semi-structured, not all questions can be anticipated. Follow-up questions will be determined by your child's answers. The interview will take place in 2 separate sessions, each lasting about 1 hour, so the total time needed for this study is about 2 hours.

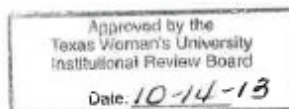
Interviews will be audio recorded. The recordings are used to make written transcripts of the interviews. These transcripts will be analyzed by the researcher..

Your permission is needed so that the researcher may interview your child for the study. Any person's participation in this study is purely voluntary. A statement of agreement to participate will be obtained from your adolescent if you give permission.

Potential Risks

Potential risks related to your child's participation include possible fatigue or anxiety. Your child may take breaks during the interview as needed. If your child experiences discomfort at any time, your child may stop the interview.

Another possible risk as a result of your child's participation in this study is release of confidential information. There is a potential risk of loss of confidentiality in all e-mail, downloading, and internet transactions.



\_\_\_\_ Initials

We will minimize these risks in the following ways: A code, rather than your child's real name, will be used on the survey/assessment papers. Hard copies of the survey completed will be stored in a locked filing cabinet on the TWU campus. If identifiable information is stored in electronic form, a password protected flash drive and/or computer device will be used. Information stored on computer hard drive will identify participants by code. The master list containing the participants' names matched to their codes will be kept in a separate locked file cabinet on the TWU campus. Identifiable information will be destroyed within 3 years of completion of the study. Hard copy identifiable data will be destroyed by shredding and disposal of shredded paper in trash system. Identifiable electronic data will be destroyed by deletion of information from drive. It is anticipated that the results of this study may be published in research publications. No real names or other identifying information will be used in any publication. **Confidentiality will be protected to the extent that it is allowed by law.**

An additional risk of participation in this study is the experience of feeling coerced to participate. To minimize the risk of coercion, we will take the following steps:

5. The principle investigator will not be professionally affiliated with the agency from which participants are recruited
6. We will not recruit participants from among the individuals or families who have been served by the principle investigator within the last 6 months.
7. You are informed that your decision to participate or decline participation will not affect the services your child receives through any agency or individual from which you may have received recruitment information.
8. You may decline participation in the study simply by not contacting the principal investigator or by indicating now or at any time that you do not want to participate.

The researchers will try to prevent any problem that could occur because of this research. You should let the researchers know immediately if there is a problem and they will help you. TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

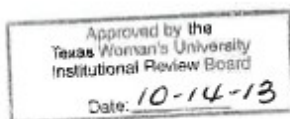
#### Participation and Benefits

Your child's involvement in this research study is completely voluntary. You or your child may discontinue your child's participation at any time without penalty. There are no direct benefits of participation in this study. You will receive a summary of the results of the study upon its completion if you request it. \*

#### Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

Initials





Consent for Participation (Study 2)

When you sign this form, **you are giving permission for your child to participate in this research.** You may revoke or cancel your permission and withdraw from this study at any time while the study is being carried out by contacting the researchers.

\_\_\_\_\_  
Signature of Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Child's name

Minor's Assent Statement (Study 2)

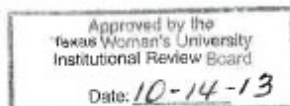
I want to participate in this research. I understand that I will be interviewed and asked to talk about the activities I do with other people and how I feel about them. I will need to meet with Ms. Lampert 2 times for about an hour. I understand that I can change my mind about participating at any time and for any reason without consequences.

\_\_\_\_\_  
Child's Signature of Assent

\* If you would like to receive a summary of the results of this study, please provide an address to which it may be sent:

\_\_\_\_\_

\_\_\_\_\_  
(Initials)



**Texas Woman's University  
Consent to Participate in Research  
Participation in Study 3**

Title: Lived Experience of social participation patterns: Visually impaired adolescents and their parents

Investigator: Jessica Lampert, MA  
Telephone: (214)205-9023 E-mail: [jlampert@att.net](mailto:jlampert@att.net)

Advisor: Catherine Candler, PhD  
Telephone: (214)706-2350 E-mail: [ccandler@twu.edu](mailto:ccandler@twu.edu)

Explanation and Purpose of the Research

You are invited to take part in a research study. The study is part of Ms. Lampert's degree requirements at Texas Woman's University. One goal of this study is to learn more about the social participation of visually impaired teens. Another goal is to compare the activities of visually impaired teens to those of sighted teens. A third goal is to learn about the experiences and views about social participation of parents of visually impaired teens.

Research Procedures

This study asks for your time and participation as a parent. You will be interviewed about the way you view your child's participation in typical social activities. The estimated time commitment for this study is one hour. This interview will take place at a time and in a place agreed on by you and the investigator. A follow-up visit requiring approximately 30 minutes will take place either in-person or via telephone.

Interviews will be audio recorded. The recordings are used to make written transcripts of the interviews. These transcripts will be analyzed by the researcher.

Your consent is needed so that the researcher may interview you. Any person's participation in this study is purely voluntary.

Potential Risks

Potential risks related to your participation include possible fatigue or anxiety. You may take breaks during the interview as needed. If you experience discomfort at any time, you may stop the interview.

Another possible risk to you as a result of your participation in this study is release of confidential information. There is a potential risk of loss of confidentiality in all e-mail, downloading, and internet transactions.

Approved by the  
Texas Woman's University  
Institutional Review Board  
Date: 10-14-13

\_\_\_\_\_ Initials

We will minimize these risks in the following ways: A code, rather than your real name or your child's, will be used on the interview papers. Hard copies of the interview completed will be stored in a locked filing cabinet on the TWU campus. If identifiable information is stored in electronic form, a password protected flash drive and/or computer device will be used. Information stored on computer hard drive will identify participants by code. The master list containing the participants' names matched to their codes will be kept in a separate locked file cabinet on the TWU campus. Identifiable information will be destroyed within 3 years of completion of the study. Hard copy identifiable data will be destroyed by shredding and disposal of shredded paper in trash system. Identifiable electronic data will be destroyed by deletion of information from drive. It is anticipated that the results of this study may be published in research publications. No real names or other identifying information will be used in any publication. **Confidentiality will be protected to the extent that it is allowed by law.**

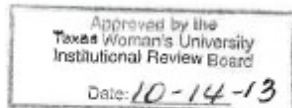
An additional risk of participation in this study is the experience of feeling coerced to participate. To minimize the risk of coercion, we will take the following steps:

9. The principle investigator will not be professionally affiliated with the agency from which participants are recruited
10. We will not recruit participants from among the individuals or families who have been served by the principle investigator within the last 6 months.
11. You are informed that your decision to participate or decline participation will not affect the services your child receives through any agency or individual from which you may have received recruitment information.
12. You may decline participation in the study simply by not contacting the principal investigator or by indicating now or at any time that you do not want to participate.

The researchers will try to prevent any problem that could occur because of this research. You should let the researchers know immediately if there is a problem and they will help you. TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

#### Participation and Benefits

Your involvement in this research study is completely voluntary. You may discontinue your participation at any time without penalty. There are no direct benefits of participation in this study. You will receive a summary of the results of the study upon its completion if you request it. \*



  
\_\_\_\_\_ Initials

Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any question about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

Consent for Participation:

When you sign this form you are agreeing to participate in this research study. You may withdraw from this study at any time while the study is being carried out by contacting the researchers.

\_\_\_\_\_  
Signature of Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Child's name

\* If you would like to receive a summary of the results of this study, please provide an address to which it may be sent:

\_\_\_\_\_

\_\_\_\_\_  
Initials

Approved by the  
Texas Woman's University  
Institutional Review Board  
Date: 10-14-13

**Texas Woman's University  
Consent to Participate in Research  
Study 1 (typically sighted)**

Title: Lived Experience of Social participation patterns: Visually impaired adolescents and their parents

Investigator: Jessica Lampert, MA  
Telephone: (214)205-9023 E-mail: [jlampert@att.net](mailto:jlampert@att.net)  
Advisor: Catherine Candler, PhD  
Telephone: (214)706-2350 E-mail: [ccandler@twu.edu](mailto:ccandler@twu.edu)

Explanation and Purpose of the Research

Your child is invited to take part in a research study. The study is part of Ms. Lampert's degree requirements at Texas Woman's University. One goal of this study is to learn more about the social participation of visually impaired teens. Another goal is to compare the activities of visually impaired teens to those of sighted teens.

Research Procedures

As part of the study, the Ms. Lampert will ask your child questions about what he or she does during the day. A formal assessment will be used as the interview. If you would like to see the questions that will be used, please ask Ms. Lampert and it will be provided. Your permission is needed so that the Ms. Lampert may interview your child for this study. Any person's participation in this study is purely voluntary. A statement of assent/agreement to participate will be obtained from your adolescent if you give permission.

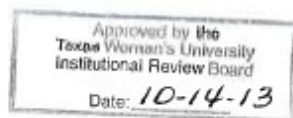
Potential Risks

Potential risks related to your child's include possible fatigue or anxiety. Your child may take breaks during the interview as needed. If your child experiences discomfort at any time, he or she may stop the interview.

Another possible risk as a result of your child's participation in this study is release of confidential information. There is a potential risk of loss of confidentiality in all e-mail, downloading, and internet transactions.

We will minimize these risks in the following ways: A code, rather than your real name or your child's, will be used on the survey/assessment papers. Hard copies of the survey completed will be stored in a locked filing cabinet. If identifiable information is stored in electronic form, a password protected flash drive and/or computer device will be used.

\_\_\_\_\_(Initials)



Information stored on computer hard drive will identify participants by code rather than name or other identifiable feature. The master list containing the participants' names matched to their codes will be kept in a separate locked file cabinet on the TWU campus. Identifiable information will be destroyed within 3 years of completion of the study, anticipated by 5/1/14. Hard copy identifiable data will be destroyed by shredding and disposal of shredded paper in trash system. Identifiable electronic data will be destroyed by deletion of information from drive. It is anticipated that the results of this study may be published in research publications. No real names or other identifying information will be used in any publication. **Confidentiality will be protected to the extent that it is allowed by law.**

An additional risk of participation in this study is the experience of feeling coerced to participate. To minimize the risk of coercion, we will take the following steps:

1. You may decline participation in the study by indicating now or at any time that you do not want to participate.
2. Although visually impaired participants may be requested to suggest sighted friends for this study, they will not be informed by the researcher who declined or who participated.

The researchers will try to prevent any problem that could occur because of this research. You should let the researchers know immediately if there is a problem and they will help you. TWU does not provide medical services or financial assistance for injuries that might happen because you are taking part in this research.

#### Participation and Benefits

Your involvement in this research study is completely voluntary. You may discontinue your participation at any time without penalty. There are no direct benefits of participation in this study. You will receive a summary of the results of the study upon its completion and upon your request. \*

#### Questions Regarding the Study

You will be given a copy of this signed and dated consent form to keep. If you have any questions about the research study you should ask the researchers; their phone numbers are at the top of this form. If you have questions about your rights as a participant in this research or the way this study has been conducted, you may contact the Texas Woman's University Office of Research and Sponsored Programs at 940-898-3378 or via e-mail at [IRB@twu.edu](mailto:IRB@twu.edu).

#### Consent for Participation:

When you sign this form **you are giving permission for your child to participate in this research.** You may revoke or cancel your permission and withdraw from this study at any time while the study is being carried out by contacting the researchers.

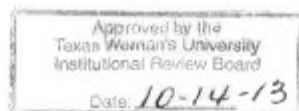
\_\_\_\_\_  
Signature of Parent/Guardian

\_\_\_\_\_  
Date

\_\_\_\_\_  
Child's name

#### Minor's Assent Statement

I want to participate in this research. I understand that I will be interviewed in different ways and that I will be asked to talk about the activities I do with other people and how I feel about them.



I will need to meet with the researcher at least 3 times for about an hour each time. I understand that I can change my mind about participating at any time without consequences.

\_\_\_\_\_  
Child's Signature of Assent

\* If you would like to receive a summary of the results of this study, please provide an address to which it may be sent: \_\_\_\_\_

\_\_\_\_\_ (Initials)

Approved by the  
Texas Woman's University  
Institutional Review Board  
Date: 10-14-13