

THE LIVED EXPERIENCE OF CHILDHOOD PLAY: RETROSPECTIVE  
ACCOUNTS AS REPORTED BY ADULTS WHO HAVE BEEN LEGALLY BLIND  
SINCE THEY WERE CHILDREN

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## DEDICATION

To my parents, brother, and grandmother. I love you to the moon and back. Thank you for your love and encouragement throughout my life. You never treated me differently from anyone else. You helped me embrace my blindness as a part of my identity without letting it define who I am. Thank you for having faith and confidence in me and for never underestimating my abilities. You always believed I could do and be anything I chose. Thank you for showing me how to balance self-advocacy with picking my battles. Thank you for teaching me that falling down simply offers me the chance to prove that I can get back up again.

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dog of 8.5 years only 2 years into this program, you faithfully attended every class with me. I always said that you made me do all the work, but you made the grade. You have been retired for 4 years now, and I am grateful you are still my buddy.

## ABSTRACT

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### THE LIVED EXPERIENCE OF CHILDHOOD PLAY: RETROSPECTIVE ACCOUNTS AS REPORTED BY ADULTS WHO HAVE BEEN LEGALLY BLIND SINCE THEY WERE CHILDREN

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The purpose of this qualitative, retrospective, phenomenological study was to explore the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. Both family systems and sociocultural theories were used as a lens through which each participant's unique experience could be viewed. A phenomenological approach allowed the researcher to capture the meaning each participant made of their experiences with childhood play. Semi-structured interviews were conducted with the participants who agreed to undergo the study. All participants were adults who have been legally blind since childhood. Twenty-three interviews were digitally recorded and transcribed verbatim. Four interviewees submitted their responses via email. All data were analyzed for emergent themes. Three themes were extrapolated from the data: 1) Parental Attitude and Involvement, 2) Sibling Inclusion, and 3) Peer Isolation. Selected quotations from participants' responses are included to illustrate the identified themes. A discussion of the results was provided, along with drawn

conclusions, implications, and limitations of the research. Recommendations were made for marriage and family therapists, service providers, and for future research.

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## CHAPTER I

### INTRODUCTION

Children with disabilities including blindness have access to more social services in the United States than in the past through the Individuals with Disabilities Education Act (IDEA) and Vocational Rehabilitation services, which help people with disabilities gain independence and eventual employment (Paylo, 2011). However, only 37% of adults who are blind in the United States are employed as opposed to 80% of their counterparts with sight (Bell & Mino, 2015). For children who are blind, general parental attitudes regarding their capabilities largely influence their identity development. The influence of play on the overall development of children who are blind could be a predictor of employment outcomes, long-term success, and their overall well-being as they get older. This also applies to children who are sighted, but extra efforts must be made in order to promote development across the lifespan in children who are blind (Sacks & Wolffe, 2006). For instance, children who are sighted are able to engage in early social-emotional development by the reciprocity of joint attention between caregiver and child, which takes place through the visual channel. However, children who are blind are unable to learn through visual observation and need their social world brought to them.

One way to bring the social world to a child who is blind is through play, which is the foundational building block of development for all children (Parten, 1932). Play teaches children creativity, critical thinking, collaboration, and communication (Dominguez & Dominguez, 1991). However, Dominguez and Dominguez (1991) noted that families of children who are blind tend to be extremely overwhelmed by coping with the diagnosis and finding appropriate services that play may not necessarily be a high priority for them. Consequentially, children who are blind may quickly fall behind their sighted counterparts.

Therefore, children who are blind may lack the opportunities to learn the necessary social skills and enhance their development in the safety net of play. Instead, they may receive feedback regarding specific social behaviors or inappropriate displays of emotion that could negatively affect peer relationships and advancement in certain realms (Roe, 2008).

### **Statement of the Problem**

Limited research has been conducted regarding the play preferences of children who are blind and how to teach these children various social skills. I did not find any retrospective research related to adults who are blind regarding their lived experiences of childhood play and any potential links between play and their overall development across the lifespan. Neither did I find any research that indicates family therapists are aware of how to help parents and family members of children who are blind understand the implications of blindness on childhood play and development. Therefore, I conducted this study in an effort to fill this missing information.

### **Purpose of the Study**

The purpose of this qualitative, retrospective, phenomenological study was to explore the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. Therapists can use information from this study to help families navigate the adjustment process of having a child who is legally blind, especially when caregivers might feel stuck in terms of knowing how to interact with the child through play.

### **Research Question**

To fulfill the purpose of this study, the following research question was explored: What are the lived experiences of childhood play as reported by adults who have been legally blind since they were children?

## Definitions

The following definitions are used in this study.

*Distance Visual Acuity:* Distance visual acuity refers to how far away a person can see an object (Dutton & Lueck, 2015). Perfect visual acuity is considered to be 20/20 in each eye, which is expressed as 20/20 OU. If an object is 20 feet from a person with 20/20 vision, then the person would have no difficulty seeing it. However, if a person's distance visual acuities are 20/200 OU, what a person with perfect acuities could see at 200 feet away, the person with 20/200 vision needs to be 20 feet from it in order to see the object. Someone may have a different visual acuity in each eye. The right eye is expressed as OD, and the left eye is expressed as OS.

*Field Restriction:* Field restriction refers to a reduced visual field, which is measured in degrees of field loss (Dutton & Lueck, 2015). A person can experience field loss in any or all of the visual fields (i.e., nasal, peripheral, and central). A person with 20/20 vision could potentially have a field restriction that results in either a visual impairment or legal blindness.

*Human Development:* The biopsychosocial development of a person across the lifespan (Baltes, 1987). Development encompasses a person's ability to grow, mature, evolve, and adapt over time. The primary developmental domains are social-emotional, physical motor, cognitive, and language.

*Play:* A variety of complex activities and a set of conscious cultural practices that allow people to construct knowledge, process information, engage in reflection, and participate in activities for enjoyment, recreation, and relaxation (Frost, Wortham, & Reifel, 2012; Parten, 1932).

*Legal Blindness:* A person is considered legally blind if distance acuities are measured at 20/200, best corrected, in the better eye, or a field restriction of 20 degrees or less, best corrected, in the better eye (Dutton & Lueck, 2015).

*Visual Impairment:* A person is considered to have a visual impairment if distance visual acuities are measured at 20/70, best corrected, in the better eye, or a field restriction of 30–21 degrees, best corrected, in the better eye (Dutton & Lueck, 2015). The Department of Motor Vehicles uses the criteria for visual impairment as the cut-off point for eligibility to receive a driver's license without special permission from a Low Vision Specialist.

### **Assumptions**

The following research assumptions applied to both the participants and the researcher:

1. Participants were open and honest in their responses.
2. Participants understood the interview questions.
3. Participants were able to recall their childhood experiences regarding play.
4. Participants voluntarily completed the entire interview process for the study.
5. The researcher both monitored and recognized her own biases and attempted to set them aside.

### **Delimitations**

The following delimitations were used in this study:

1. The research sample included adults at least 18 years of age who were either born legally blind or who received a diagnosis of legal blindness during early childhood. All participants were legally blind, so that lack of a visual frame of reference could be studied in order to assess outcomes related to the impact that play may have on the development of children who are blind.
2. Participants must not have had additional diagnoses as children.
3. Interviews were conducted via telephone in order to reduce scheduling complications and eliminate location as a barrier to participation.

4. Participants were required to be able to speak and understand English at approximately the fifth-grade level.

### **Researcher Reflexivity**

I am currently a Doctoral Candidate in the Marriage and Family Therapy program at Texas Woman's University. I am a Licensed Professional Counselor and a Certified Rehabilitation Counselor. I worked for the state of Texas for 12 years in the Division for Blind Services. I held positions as a Vocational Rehabilitation Teacher, Transition Vocational Rehabilitation Counselor, and Blind Children's Specialist. I am currently in private practice as a therapist. Based on both my professional and personal experiences, I have noticed differences between how children who are blind and children who are sighted play. As I myself am blind, it was important to bracket my assumptions and stay as neutral as possible during both the data collection and the data analysis process.

I had extremely positive childhood experiences with play. My parents and family have always encouraged me to pursue all of my interests. However, I also received negative feedback from my sighted peers and sibling regarding some of my preferred activities and methods of play during early childhood. This feedback may have stifled some of my creativity, especially when it comes to free play, as well as led to some insecurities and self-consciousness about play in general. Furthermore, I believe that my understanding is limited regarding nonverbal cues such as gestures and facial expressions.

In my late elementary school years, I retreated into books instead of free play activities. In fact, I once tried to get my mother to write a note to excuse me from recess so I could stay inside and read. Of course, she did not comply. As a young child, I excelled at functional and sociodramatic play, but I am still unable to grasp and struggle with concepts of representational

play. I preferred structured play over free play, due to feelings of self-consciousness and not knowing what to do. I had an aversion to touching specific textures like glue and paint.

While I engaged in cooperative play led by my peers and me, I also had my own preferred activities. For example, I would open and close the front door, pretending I was letting children on and off of the school bus. I also enjoyed singing into a tape recorder and listening to myself. I reenacted movies or TV shows I had recently watched, either by myself or I asked others to do so with me. I fixated on specific sounds, like the sound of the school bus door and the bus steps as people got on and off. I also loved listening to water go down the drain, as well as to the clinking of dishes and silverware. One year, I wanted a stage and a microphone for Christmas, primarily based on the sounds they made (i.e. the reverberation of the microphone and the sound of the stage floor when it was walked upon). I still love performing for audiences, whether I am on stage, giving a presentation, or recording an episode of The Unique Abilities Podcast, which I launched in order to bring information about disability-related topics to a larger audience.

During my mid-elementary school years, I engaged in parallel play with a friend who was blind over the telephone. We both played music at the same time, singing along to different songs while pretending we were other people performing in a talent show.

We also role-played over the phone stories we made up as we went along. When I was alone in my grandmother's swimming pool as a young child, I entertained myself for hours by having imaginary friends take swimming lessons. I spoke both with and for them.

I have always had trouble distinguishing embossed figures, such as a dog on a birthday card. On a spring break trip during my freshman year of college, I

helped build my first snowman. I was shocked and surprised that the figure consisted of huge clumps of snow and snowballs stacked on top of one another. I thought we would make a full outline of a person, including shaping the snow into arms, legs, torso, and face. A real snowman did not feel at all how I had it pictured in my mind. This experience helped me begin to understand how to think and process information in less literal and concrete terms.

As an adult, I have begun to embrace play and am more inclined to let myself be and look silly. In my work, I encourage parents to promote and normalize their children's free play. I have purchased developmental toys with caseload funds for my clients to promote the development of play, social, cognitive, language, and motor skills, as well as to increase sensory exploration. Based on my own experiences, I made a conscious effort to bracket my assumptions during both the collection and the analysis of data.

### **Summary**

I conducted a qualitative, phenomenological, retrospective study that explored the lived experiences of childhood play as reported by adults who were legally blind as children. This chapter included information related to researcher reflexivity and assumptions. The delimitations of the study include age of participants, age of onset of blindness, parameters regarding additional diagnoses, and the ability to speak and understand English.



## CHAPTER II

### REVIEW OF RELEVANT LITERATURE

In reviewing the literature, it became apparent that there has been research conducted on family systems and disability, as well as some literature pertaining to strategies for increasing opportunities for children who are blind to play and how to teach them social skills (Willings, 2016). However, there seems to be a gap in the literature pertaining to the links between how children who are blind prefer to play, the types of play in which they engage, and messages they receive from others about their play that impact their development across the lifespan, self-confidence, and peer relationships through adulthood. I did not find any retrospective studies pertaining to the childhood experiences of adults who are legally blind regarding play.

This literature review examines both family systems theory and sociocultural theory, as well as research that has been done as it relates to play and development (especially in terms of social skills) with regard to children with disabilities, including visual impairment in a general sense. The studies focus on the families' needs, perceptions, and emotions as they relate to having a child with a disability. Concepts include the needs of siblings without disabilities, as well as making emotional connections and teaching social skills to children who are blind.

#### **Theoretical Framework**

For the purposes of this study, both family systems theory and sociocultural theory laid the foundation for how the study was conducted. Concepts from both theories can be applied hand-in-hand to facilitate the development of children who are blind. Family systems theory is steeped in familial patterns and interdependence (Bowen, 1978). Sociocultural theory is

systemic in nature, because it is founded upon interactions within varying contexts (Vygotsky, 1978). The following discussion offers a brief explanation of each theoretical lens.

Murray Bowen (1978) expanded concepts from general systems theory in his family systems therapeutic model in the early 1950s when he studied patients who were hospitalized with a diagnosis of schizophrenia. A family system consists of members who share common characteristics, interactions, and interdependence on one another (Bowen, 1978). A healthy family system is compared to a well-oiled machine (Hanson, 1995). Unlike a machine that is a closed system interacting solely with its own parts, families are open systems that interact and share information with subsystems and suprasystems, such as the environment. Family therapists are able to unearth deeply rooted patterns within a family by focusing on the positive and negative processes within the system.

Systems theory views causality as circular, not linear (Bowen, 1978). In traditional theories, the normative view is that A causes B, and before causes after (Hanson, 1995). In circular causality, every action causes a reaction; within families, a change in one member results in a change in the system as a whole. In other words, actions on a system will reverberate through existing patterns. Events depend on patterns, not stimuli. In regard to circular causality, blame does not have a place within a systemic approach, and the question why is not asked. All parts of the system play a role and are accountable in some way for both healthy and problematic situations (Hanson, 1995). Blame involves separating parts of a system, isolating a causal factor, and shouldering it with fault. The word responsibility has less negative connotations and is more easily shared; even in traumatic events, the so-called victim has certain choices in how to move forward and deal with the aftermath.

Theoretical exploration of social development began with social learning theory where behaviorism was challenged by Albert Bandura (Bandura & Walters, 1977). Bandura argued that behavior is not merely a conglomeration of learned responses through conditioning; people interact with, create, and change their environment. People tend to selectively model or imitate what others do depending on context and without reinforcement (Bandura & Walters, 1977). Since children who are blind cannot visually observe social cues or behaviors, they do not easily mimic others. It is vital that they receive verbal prompts and feedback, physical modeling when appropriate, and consistent, as well as realistic, instruction and reinforcement of their performance and of vision-dependent behaviors (Willings, 2016).

Sociocultural theory also emphasizes that development stems from social and cultural interactions, creating active learning experiences (Sacks & Wolffe, 2006). Active learning can be described as an interaction between a person and her or his environment. Lev Vygotsky (1978) proposed a sociocultural framework for active learning and child development heavily influenced by Marxism. Vygotsky was able to expand Marxist ideas when describing the ways in which children develop. Karl Marx (1859) argued that movement generates thinking. He also viewed development as a process occurring within historical contexts and is advanced through dialectical exchanges.

Vygotsky (1978) proposed that as children grow, develop, and interact with their environment, they learn how to perform various activities while presented with challenges. As these challenges arise, children use problem-solving skills to increase their knowledge base. Vygotsky (1967) viewed play as the bridge for linking cognitive, language, motor, and social-emotional development. Play can provide a safe and natural environment for experiencing and experimenting with new concepts in order to build self-confidence. Vygotsky theorized that

children enhance their problem-solving skills through imaginative play. For instance, children in preschool lay the foundation for abstract thinking by developing the ability to conceptualize events and objects that are not within reach. By depending less on tangible props and engaging in complex pretend play, children learn emotional self-regulation, as well as develop the ability to incorporate figurative language and thoughts into their worldview.

Vygotsky (1978) viewed development as a historical process within cultural contexts. Social interactions lead both children and adults to undergo continuous changes in both their thoughts and patterns of behavior that are influenced by cultural contexts. Development depends on the ways in which a person interacts with the people and tools the culture provides in order to shape a person's worldview. Vygotsky referred to these tools as signs and claimed that human behavior cannot be understood without thoroughly examining the cultural signs of an individual.

Neuroscience and neurobiological research indicates that social-emotional and cognitive processes are interrelated (Bell & Wolfe, 2004). Emotional and cognitive brain mechanisms inform the same functions, like helping a person recognize specific situations and influencing their behavior. Vygotsky's (1978) sociocultural framework views cognition and social context as inseparable. He was interested in the varying cognitive competencies among diverse groups, including people with intellectual disabilities. He posited that children construct their own knowledge, but specific skills are taught by those who are more skilled in the particular area of study (Vygotsky, 1978).

Active apprenticeship is a core tenet of sociocultural theory, as interdependence is seen as vital for learning to take place. In order for the apprentice to learn, the mentor must locate the zone of proximal development, which is the gap between what a person can achieve alone and

what a person can achieve through problem-solving with a teacher, parent, or peer (Vygotsky, 1978). Scaffolding (a term coined after Vygotsky's death) describes the assistance provided when helping a child reach beyond the lower limits of the zone of proximal development in order to provide more advanced problem-solving skills (Bruner, 1961). Psychologist Berthold Lowenfeld (1964) stated that there are three primary limitations imposed on the development of children who are blind: loss of range and varying experiences, loss of the ability to travel and independently explore the environment, and loss of control regarding the self in relation to the environment. Lowenfeld noted that children with visual impairments require more one-on-one, specialized experiences with concrete materials allowing for active exploration to help them make sense of their world. According to Gunaratne (2016), some scaffolding strategies that parents and teachers can implement for enhancing the development of children who are blind include providing descriptive, sequential information to make up for the child's lack of visual references, describing and tactually demonstrating social cues including body language, providing stimulating activities to promote spatial awareness and control, reducing visual clutter/complexity, and providing tactual interactions to increase motor development.

### **Social-Emotional, Motor, Cognitive, and Language Development**

Social-emotional development encompasses a person's ability to build and maintain relationships, as well as the ability to manage, regulate, and identify emotions in the self and others (Baltes, 1987; Bandura & Walters, 1977; Cohen, Onunaku, Clothier, & Poppe, 2005). Through responsive caregiving, infants start both imitating social cues and recognizing facial expressions. Infants respond early on by making eye contact and recognizing their caregivers' voices. High quality relationships are the foundation of an infant's positive social-emotional development (Bandura & Walters, 1977). These secure attachments make it easier for a child to

develop empathy and to navigate peer interactions as he or she gets older (Anderson & Keltner, 2002).

Infants interact with one another by looking at or touching each other (Cohen et al., 2005). Their interactions begin to become more complex when they engage in repetitive actions, like rolling a ball back and forth. The complexity further increases through cooperative play and turn-taking (Parten, 1932). Peers experiment with different roles in a group, make up and follow rules, and learn about navigating social situations from one another.

Even the most basic interactions help children develop empathy (Anderson & Keltner, 2002). In essence, empathy is the ability for a person to understand how another person thinks and feels, without necessarily agreeing with them or having had the same experience. As an adult, empathy is vital for one to be able to develop more complex family and peer relationships, as well as to navigate school and workplace environments.

Motor skills are the learned muscle movements to perform both large and small bodily actions (Cratty, 1979). Large body movements are known as gross motor skills, and small body movements are referred to as fine motor skills. Motor skills inherently improve with both the myelination of the corpus callosum and brain lateralization; as the prefrontal cortex matures, impulse control decreases (Cratty, 1979; Murphy & O'Driscoll, 1989). Fine motor skills take more time to develop than gross motor skills, especially those involving hand movements. Most fine motor tasks involve lateral movements, such as buttoning, snapping, zipping, tying, cutting food, and writing. Gross motor activities involve the large muscles in the body which enable abilities such as rolling, sitting, standing, walking, running, jumping, skipping, and throwing (Cratty, 1979).

Motor development occurs from the inside out and from top to bottom (Cratty, 1979). This means that children typically gain control over their arms before they can control their fingers. Head control occurs prior to the control of one's legs and feet. Muscle tone (muscle strength and resistance) aids in the ability to use the muscles with ease. The vestibular and proprioceptive systems aid in balance, orientation, posture, and coordination (Murphy & O'Driscoll, 1989).

Cognitive development encompasses the ways in which children think, explore, problem-solve, and figure out the world around them (Baltes, 1987). Cognitive theory is steeped in the effect thoughts and expectations have on a person's values, attitudes toward the self and others, assumptions, and actions. Jean Piaget (considered the first cognitive theorist) postulated that what children think reveals more about them than what they know (Piaget, 1963). He observed that curiosity about the world begins in infancy and that time and experience changes thinking; thought processes affect behavior. This idea became the core tenet of cognitive theory. Piaget categorized cognition into four age-related developmental stages: sensorimotor (birth to 2 years), preoperational (2 to 6 years), concrete operational (6 to 11 years), and formal operational (12 years through adulthood; Piaget, 1963). According to Piaget, preexisting ideas serve to shape new experiences, leading to a state of mental balance known as cognitive equilibrium.

Language development is the process by which children learn to communicate through receptive understanding and outward expression of language (Baltes, 1987). Vygotsky sought to understand how thought and language interact (Vygotsky, 1978). He determined that thought and speech begin as two separate entities; over time, nonverbal thought and nonconceptualized speech merge, allowing the child to verbalize their thoughts. Conversely, Noam Chomsky (1959) viewed language from a universalist perspective, meaning that language is innate and

developed from brain advancements millennia ago in order for the human species to survive. This framework posits that language is neither taught nor socially acquired. Chomsky's Language Acquisition Device allows children to universally derive language rules from everyday speech, regardless of their particular spoken language (Chomsky, 1959). Infants have a genetic predisposition for all languages, and neuronal connections are made to support the language(s) an infant hears (Baltes, 1987).

### **Play**

Play aids in the development of motor, cognitive, language, and social skills for all children (Dominguez & Dominguez, 1991; Parten, 1932; Vygotsky, 1978). In fact, Dutton and Lueck (2015) described play as children's universal language. Both self-esteem and self-confidence grow and develop through various types of play that can either be incorporated into one another or stand alone to serve different purposes (Dutton & Lueck, 2015; Sacks & Wolffe, 2006). Solitary or solo play occurs when the child plays alone and typically does not show interest in playing with others (Parten, 1932). Children explore toys and objects through manipulative play. They may bang one object against another or on a surface to hear different sounds, mouth objects, or enhance cause and effect skills by pushing buttons on a toy in order to get a reaction. A child who plays near other children with similar and different toys while taking some interest in what the other children are doing is known as parallel play. When children engage in representational or symbolic play, they pretend that one object is another (i.e., using a pen as a microphone or using a table as a stove; Gilpin, Brown, & Pierucci, 2015; Sacks & Wolffe, 2006). Functional play is the use of toys and objects as in reality, such as playing tea party with toy cups and saucers or pretending to drive with a toy vehicle. Children engage in



cooperative play when they interact with one another and practice turn-taking. Sociodramatic play occurs when children take on a fantasy role, pretending to be someone or something else.

Parten (1932) claimed that acquiring play skills serves as the basis for positive and successful social encounters in school and employment as an adult. Sacks and Wolffe (2006) pointed out that children who are blind may be delayed in developing play skills. These children face numerous social challenges (Dutton & Lueck, 2015; Zihl & Dutton, 2015). They may have difficulty locating toys, finding a friend on the playground, reading facial expressions, and moving freely in play areas. They may engage in adaptive behaviors and repetitive play that mimics some symptoms of autism spectrum disorder. These self-stimulating mannerisms are known as blindisms and include, but are not limited to, rocking, tapping, spinning, eye-rubbing, head-banging, head-swaying, and finger-flicking (Landau, 1997).

### **Linking Development and Play**

Knowledge of the typical developmental stages of play may help families, educators, and service providers better understand how vision loss affects socialization. Tröster and Brambring (1994) found that the primary differences in how children who are blind play compared to their sighted peers were that children who are sighted tend to develop more complex play skills at an earlier age, sighted children interact with other peers more frequently, and children who are blind prefer tactile and auditory toys to symbolic games. Tröster and Brambring urged parents and educators to keep play actions similar to reality. Preisler (1993) discussed similar findings. Preisler noted that the majority of children who are blind between 2 and 3 years of age exhibit explorative behaviors, rather than engage in simple pretend play in the home environment. During a study in a preschool setting, children who were blind rarely took an interest in the play of sighted peers and did not typically initiate interactions with them. It was reported that

teachers had a difficult time understanding the way in which the children who were blind functioned and needed information presented. Celeste (2006) claimed that while children who are blind and who present with no other diagnoses may be developmentally on or above target for their age, they may display limited play behaviors, and their social interactions may be compromised. Bell and Mino (2015) noted these limitations have a potentially devastating effect on employment outcomes as children who are blind age and move into the workforce. Complex play skills and social interactions teach children soft skills that are vital for giving and receiving feedback, getting along with others, and higher levels of creativity that are critical for success as adults in a variety of environments.

### **Stress, Crisis, and Chronic Sorrow**

Having a child with a disability can cause emotional upheaval within a family system and force its members to restructure how each member contributes to the family, as well as family-work role division between partners (Trute, Benzies, & Worthington, 2012). Family members may find themselves forced to adapt and cope in ways that test their resilience (Bragg & Brown, 1992). Adaptation is defined as the ability for a family to change with little disruption to the system (Lavee, 2013). Taanila, Syrjälä, Kokkonen, and Järvelin (2002) defined coping as managing stress by using existing resources and strategies developed by experiencing previous stressor events. The aim of familial coping is to either maintain or restore the balance between resources and demands. Resilience is defined as the ability to bounce forward from an adverse situation (Walsh, 2006). It is not seen as bouncing back, because resilience involves growth that enables a person to become stronger and more resourceful than prior to the adverse situation. Circumstances seen as adverse can either be classified as stressor events or lead to crisis (Boss, 2002). Stress merely implies change in the family system, while crisis immobilizes the family.

Raising a child who is legally blind can be daunting to parents and other family members (Kirby-Green & Moore, 2001). Parents may experience stress and go into crisis mode if unable to cope with their child's visual impairment. Having a child who is blind can activate stress or lead to crisis and cause a disruption within the family system, depending on familial support and relationship cohesion (integration; Kirby-Green & Moore, 2001). Armour (2006) stated that unresolved grief can be a cause for parental separation and/or divorce. Based on family of origin views and upbringing together with differences in resilience, couples are highly likely to have different reactions when their child is diagnosed with a disability (Rolland, 1994). Olshansky (1962) coined the term *chronic sorrow* to describe grief experienced by parents of children with disabilities that is related to a permanent cyclical living loss that is ongoing and progressive. Family functioning is most impacted by parental stressors related to a child's disability during times of diagnosis and developmental transitions, as parents may experience the loss of not having a "typical" child and fear that the child may not be as independent or live the quality of life the parents anticipated (Gordon, 2009). Chronic sorrow encompasses the episodic feelings of sadness some parents may experience while performing tasks associated with taking care of a child with special needs. In some families, the loss may not be spoken of openly as life moves along and becomes more routine. However, not mourning a mutual loss can lead to significant dysfunction within the structure of the family system (Armour, 2006).

### **Play, Familial Bonding, and Development**

Howe (2006) discussed the effects of chronic sorrow on play and attachment. It is possible for parents to be overwhelmed and so highly focused on their chronic sorrow that attention paid to parent-child interactions such as play can be minimized. Not only does this affect play between parents and children who are blind, but the needs of siblings may be

unintentionally overlooked. This can negatively affect sibling relationships, including how the sibling who is sighted plays with and provides social feedback to the child who is blind (Arnold, Heller, & Kramer, 2012). Siblings may feel like the family does not pay enough attention to their needs. Siblings may then feel guilty for wanting and demanding attention from the family which might take away attention from the child who is blind. A child who is blind in turn may feel as if she or he is unable to participate in activities as their siblings do. Conversely, siblings are often inclined to be more honest than peers regarding unmentionable habits or characteristics of a child who is blind (Sacks & Wolfe, 2006). Siblings may be adept at ensuring equal treatment and attention from their parents. It is vital for service providers to address the needs of the entire family system to promote satisfaction within relationships, cohesion, resiliency, and to strengthen familial bonds.

Often, parents do not know how to play and interact with a child who is legally blind in a way that ensures that the child is able to make connections through language and emotional expression that lead to the understanding of social cues needed to successfully interact with peers and adults (Campbell, 2007). Parents may not understand how to teach a child who is blind about the world around them. They have to be creative since they cannot point out objects to the child. Children who are blind perceive their world in parts before they can understand whole concepts (Dominguez & Dominguez, 1991; Zihl & Dutton, 2015). Information is slowly integrated into a holistic framework. Perceiving parts prior to a whole continues throughout the adult life of someone who is blind. Jacko, Mayros, Brady-Simmons, Chica, and Moore (2013) explained that children who are blind, like all children, need a frame of reference when a new object is being described. However, children who are blind are unable to process fine and gross motor movements, language, and meaning through vision. Everyday activities can lead to

preliteracy concepts that strengthen explicit memory, teach sequencing, and prepare the child for reading comprehension and storytelling (Dote-Kwan & Hughes, 1994).

Jacko et al. (2013) described the difference between using hand-over-hand and hand-under-hand techniques to teach someone who is blind how to perform new activities. Hand-over-hand involves grabbing someone's hand and placing it on what is to be explored with the explorer's hand underneath the hand of the parent or teacher. This can be quite traumatic for someone who cannot see; for instance, their hand may come in contact with something sticky or with some other texture that is unappealing. Jacko et al. pointed out that it would be inappropriate to grab someone's eyes to force them to look at something. Therefore, it is equally inappropriate to force someone to touch something (Jacko et al., 2013). Hand-under-hand is when the parent's or teacher's hands are on the object. Their hands slip underneath the child's hands and are in between the child and the object. The parent or teacher may play with an object next to the child's hands, giving the child the opportunity to reach out and initiate exploration. By describing objects and increasing positive exploration techniques such as hand-under-hand, children who are blind are better able to decrease tactile defensiveness and issues related to sensory integration. They are also able to increase finger isolation, which is important for letter distinction if the child is going to be a Braille reader (Jacko et al., 2013).

The above concepts are also relevant to a child's ability to engage in a wide variety of play activities. Purposeful play and intentional movement can help children who cannot see more fully understand visual concepts and enhance their desire to explore their environment. Because emotional intelligence and social development are largely derived from subtle nonverbal cues, it is vital that

children with visual impairments are given time to learn the various aspects of emotional development and social cues through verbal explanations and hand- under-hand activities (Roe, 2008). Examples include verbal prompts, touch, and using a nonabrasive tone of voice. All too often, sighted peers may feel uncomfortable providing feedback related to a negative social interaction with a child who is blind. If time is carved out for more customized training in this area, then there is a higher likelihood that children who are blind will be able to strengthen their awareness of nonverbal and subtle cues, as well as increase their ability to perceive emotional states within themselves and others (Roe, 2008).

Vision is a fast, sensory process. It scans the environment and divides information into foreground and background. Children who are visually impaired do not have that ability through the visual sensory channel (Campbell, 2007). They must use their senses of touch and hearing to categorize information. The emotional development of children who are either blind or visually impaired may be at risk due to the inability of these children to share and respond to the feelings of others based on learning about language and emotion through visual cues. In typical development, eye and voice contact with parents and/or caregivers are integral in children's first relationships. However, children who are blind must primarily depend on familiar voices, as well as experiential interactions in order to understand themselves in relation to others. While visual loss may impact other areas of development, Campbell (2007) explained that a lack of early social experiences may lead to long-term difficulties in social understanding. Strategies such as providing running commentary during activities, continuous references to self, others, and objects, as well as responding to the child's cues in addition to providing prompts helps children who cannot see respond more effectively in social situations. Campbell (2007) concluded that the

construct of emotional availability can be used to describe the quality of relational interactions. Parent-child interaction is an appropriate context for intervention, because of the potential for influencing both its affective and structural qualities. Such interventions need to account for the challenges of interacting with children who cannot perceive visual cues and need to be told about what they cannot see.

The emotional development and acquisition of language should be considered when working with parents of a child with a visual impairment (Campbell, 2007). Not only is it important to teach the child, it is vital that parents are taught how to bond and interact with their child in ways that promote language acquisition and emotional development (Wilton, 2011). By teaching parents ways in which to relay nonvisual concepts to the child, parents are able to allow the child to foster growth and independence. Rettig (1994) indicated that children who are blind experience a lag in the development of language. For instance, Rettig pointed out that sighted children primarily use language to refer to past experiences and to relate objects to familiar situations. Rettig stated that children who are blind primarily use language to ask excessive questions in order to gain information about the environment. Rettig (1994) emphasized the importance of honing in on the awareness of the sense of self for children who are blind, as there appears to be a delay in the use of pronouns such as “I” and “me,” as well as the word “no.” Rettig suggested that a delay in autonomy based on the instability of the use of these words by children who are blind inhibits their ability to engage in symbolic play.

### **Summary**

The above literature review started out with brief histories of both family systems theory and sociocultural theory. Play, development, and their linkage were discussed. Concepts of stress, crisis, and chronic sorrow were outlined. I also discussed the effects of vision loss on

acquiring linguistic, cognitive, and social-emotional skills, strategies for helping to further develop these skills, and incorporating the needs of their siblings. This study has the potential to make a significant contribution to the literature by expanding on systemic strategies that will increase the positive development of children who are blind as it relates to play. When a child is legally blind, the entire family system is affected (Cook & Kenny, 2006). In this regard, both family systems and sociocultural theories can be used to help marriage and family therapists and other service providers realize that they, too, are a part of that system. They can subsequently provide tailored support and resources to the entire family. Therefore, children who are blind would be able to develop more complex play skills and normalize how they choose to engage in free play activities.



## CHAPTER III

### METHODOLOGY

I conducted qualitative, retrospective, and phenomenological research that explored the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. I found that some limited research has been conducted regarding the play preferences of children who are blind and how to teach these children various social skills. However, no retrospective research was found related to adults who are blind regarding their lived experiences of childhood play and any potential links between play and their development across the lifespan. Therapists will be able to use information from this study when working with families that include children who are legally blind to promote positive play strategies that will enhance social-emotional development. Data were collected using semi-structured interviews with adults who have been legally blind since childhood that were conducted by telephone. Interviews were digitally recorded, transcribed, and analyzed for emerging themes. This chapter presents the research methodology, research design, research approach, protection of participants, role of the researcher, sample recruitment, interview procedures, and an explanation of the procedures used for data collection and analysis.

#### **Research Design**

Phenomenology was used to conduct 27 interviews regarding the lived experiences of participants. The researcher explored childhood play and its possible impact on the participants' development by obtaining information regarding messages and feedback they received as children about play from caregivers, peers, and siblings. Based on the findings, different systemic strategies that families, teachers, and service providers can use to maximize positive

play for children who are blind and to normalize their preferred free play activities are recommended.

### **Qualitative Research Approach**

Interviewing based on the phenomenological genre was the chosen form of methodology used for this study. A phenomenological research study attempts to understand participants' perceptions, perspectives, and understanding of a specific situation or phenomenon (Van Manen, 2011). By looking at multiple perspectives of the same situation, investigators can begin making some generalizations about what something is like as an experience from the insider's perspective. A phenomenological study typically involves four steps: bracketing, intuiting, analyzing, and describing (Van Manen, 2011). Bracketing is the process of identifying and suspending preconceived notions and biases regarding the phenomenon under study. Intuiting requires that the investigator remain open to the meanings attributed to the phenomenon by those who have lived and experienced it. The investigator must creatively vary the data until such understandings emerge, as well as become completely immersed in the study. Data analysis involves open, axial, and selective coding that serves to categorize and make sense of the phenomenological meanings (Creswell, 2014). Common patterns, trends, and themes begin to emerge, and the researcher's immersion provides an avenue for pure descriptions of the phenomenon. The final step is the description phase wherein the researcher comes to understand and define the phenomenon, offering distinct, critical descriptions in written and verbal modes.

The most common ways to collect data include interviews, personal diaries and journals, observation, and art (Van Manen, 2011). In-depth interviews are most common. The goal of these interviews is to come as close as possible to understanding the participants' truths about the

experience. Investigators ask open-ended questions which urge the participant to provide deep reflections about the phenomenon (Van Manen, 2011).

### **Research Question**

The following research question was asked in order to fulfill the purpose of the study: What are the lived experiences of childhood play as reported by adults who have been legally blind since they were children?

### **Protection of Human Participants**

This study was reviewed and approved by the Texas Woman's University Institutional Review Board (IRB) so that the rights of the participants were protected. Participation in the study was voluntary and confidential, and the participants could exit the study at any time. Each participant was assigned a numeric code, to insure confidentiality. The data were electronically stored, password protected, and saved in encrypted files to reduce the risks associated with data loss or tampering. All files were stored on a password-protected computer. Each participant was provided with counseling resources, in case she or he experienced any emotional discomfort from the study.

### **Participants**

I hoped to have at least 15 participants in order to reach data saturation, which occurs when the investigator is no longer finding new material (Marshall & Rossman, 2016). I had a sample size of 27 participants, and data saturation was reached at 14 participants. The research sample included adults at least 18 years of age who were either born legally blind or who lost their vision during early childhood. All participants must be legally blind, so that lack of a visual frame of reference can be studied in order to assess outcomes related to the impact that play may have on the development of children who are blind. Participants must not have had additional

diagnoses as children. Interviews were conducted via telephone in order to reduce scheduling complications and eliminate location as a barrier to participation. Subjects were required to be able to speak and understand English at approximately the fifth-grade level.

### **Sample Recruitment**

Purposive and snowball sampling techniques were used to obtain participants for this study. Purposive sampling is a nonprobability sampling technique in which participants are recruited selectively, based on characteristics of the population that match the requirements of the study (Marshall & Rossman, 2016). Snowball sampling is also a nonprobability sampling technique wherein existing subjects recruit others from among their acquaintances or by word of mouth.

I distributed a recruitment flyer through email listservs, social media, and blindness message boards in order to recruit participants. Information about the study was also posted on my personal Facebook page. The flyer was copied and pasted directly into the email and postings, so that no additional wording was necessary. The flyer can be found in Appendix A.

Participants were asked to either email or call the researcher to express interest in the study. I personally explained the study to the interested participants either by phone or email and scheduled the interview if the subject was still interested in participating. All interviews took place by phone and were digitally recorded. I obtained consent from each participant by electronic signature through email. The IRB allowed me to obtain typed signatures from participants. The consent form can be found in Appendix B. The initial script can be found in Appendix D.

## **Data Collection**

Each participant met with me by phone once for a maximum of one hour. Each session consisted of the interview, which was recorded. Prior to asking the interview questions, demographic information was obtained. The demographic questions can be found in Appendix C. All participants were given the opportunity to schedule a second one-hour phone call with me for a follow-up that would consist of member checking and debriefing. This allows for triangulation of the data, so that multiple sources of data are used (Marshall & Rossman, 2016). Triangulation allows for the corroborating of data, which increases credibility and confirmability. It was not necessary for all participants to follow up with the researcher for member checking and debriefing. I received follow-up emails from four participants that contained additional information, which was added to their transcripts with a notation that the information was received as a follow up to the initial interview. None of the participants asked to participate in a follow-up phone interview. However, the follow-up telephone script can be found in Appendix G.

## **Interview Procedures**

Interviews took place by telephone, since the researcher and the participants were blind. Four interviewees were unable to schedule telephone interviews and submitted their responses via email. Using the telephone to conduct the interviews negated in-person scheduling complications, such as difficulty traveling. This method also allowed participants to be located anywhere. I conducted each telephone interview alone in my office with the door closed to ensure privacy in the researcher's location. Subjects were also encouraged to participate in the interview behind closed doors to ensure their privacy. All telephone interviews were digitally recorded and transcribed verbatim. I also took notes during each telephone interview in Braille

with a Braille Display connected via Bluetooth to an iPad. All files were password protected. Field notes were subsequently typed on a computer into a password protected Microsoft Word file and encrypted.

A possible risk in this study was emotional discomfort with the questions being asked. If a participant was to become tired or upset, they could take breaks as needed. Participants were also allowed to stop answering questions at any time and end the interview. I provided participants with a list of counseling resources, in case anyone felt the need to talk to a professional about their discomfort. Counseling resources that were provided can be found in Appendix F.

Another risk in this study was loss of confidentiality. Confidentiality was protected to the extent that is allowed by law. The electronic data were encrypted and password protected. Only I had access to any data collected. The data, excluding the dissertation itself, will be destroyed within 3 years after the study is completed. The results of the study may be reported in scientific magazines or journals, but names and any other identifying information will not be included. An interview guide contains the interview script, as well as a list of all interview questions and prompts (see Appendix E).

### **Role of the Researcher**

I explored the lived experience of childhood play as reported by adults who have been legally blind since they were children. I am currently a Doctoral Candidate in the Marriage and Family Therapy program at Texas Woman's University. I am a Licensed Professional Counselor and a Certified Rehabilitation Counselor. I have worked as a Blind Children's Specialist for the state of Texas and noticed differences between how both children who are blind and sighted play. As I myself am blind, it was important to bracket and stay as neutral as possible during the

data collection process by setting my own positive and negative experiences with play as a child aside. I did not want participants to answer dishonestly in order to make me feel more comfortable. I disclosed my blindness to the participants to increase the trustworthiness of the investigation. However, I did not disclose to the participants my experiences with play until after the study, and only if they asked.

### **Credibility**

For the purpose of this study, data triangulation was performed by conducting interviews as well as peer debriefing for confirmability. My dissertation committee provided a form of debriefing by viewing portions of interview transcripts, and my committee chair and one committee member gave feedback on how I could provide thicker descriptions of the data. Two research assistants were recruited and approved by the IRB to serve as co-coders. Each research assistant reviewed randomly assigned transcripts and reported on recurring statements, significant phrases, patterns, and themes they found in the data. I made every effort to ensure that participants were not misrepresented in any way.

### **Data Analysis Procedures**

Marshall and Rossman (2016) detailed step-by-step strategies and procedures for analyzing phenomenological data. First, the researcher should read the interview transcripts several times in order to organize the data. Significant statements and phrases are extrapolated from each transcript to form meaning clusters that highlight how each participant experiences the phenomenon being studied. The researcher then looks for patterns that describe the most common experiences shared by all participants (Marshall & Rossman, 2016).

Interviews were examined in relation to the research question, which pertains to the lived experience of childhood play of people who are blind. Data triangulation consisted of interview

questions, co-coding, and peer debriefing. I assigned each participant with a numeric code, starting with 01, and F if the participant identified as female, and M if male, in order to protect all identifying information. I digitally recorded and took notes in Braille during each interview. Those notes were included in the field notes typed into Microsoft Word, along with the interview transcripts and the descriptions of my observations. My dissertation director reviewed all transcripts, and the rest of the committee members viewed randomly assigned transcripts in order to point out ways in which I might consider providing a thicker description of the data. In addition to my dissertation director, one committee member responded with detailed feedback on the data. Peer debriefing provides an opportunity for others to spot emerging patterns within the data, in order to increase confirmability and add to the researcher's findings (Marshall & Rossman, 2016).

After each interview, I listened to the recording one time through before it was transcribed verbatim. First-cycle coding consisted of me opening a new password protected Microsoft Word file and typing out any words and phrases that were repeated throughout each interview. I had two approved research assistants to aid in the coding process. Each research assistant received the same eight transcripts to code, which were randomly chosen by me. Second-cycle coding involved breaking down the repeated phrases into categories across interviews in order to uncover any emergent themes (Marshall & Rossman, 2016). I met with each research assistant individually to corroborate findings. I, my two research assistants, dissertation director, and one dissertation committee member all found consistent patterns and themes within the transcripts.



## Summary

A phenomenological interviewing approach was used for data collection. Recruitment and data collection procedures were discussed. Risks and methods for participant protection were outlined, and ethical considerations regarding confidentiality and data storage were described.

I made every effort to maintain credibility and dependability by triangulating data. Data triangulation was achieved through interviews, co-coding, and peer debriefing by the dissertation director, one committee member, and two IRB approved research assistants. First-cycle coding broke down words and phrases into categories. Second-cycle coding condensed the categories into themes.

## CHAPTER IV

### RESULTS

The purpose of this qualitative, retrospective, phenomenological study was to explore the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. The interviews were digitally recorded and transcribed verbatim, and the data were analyzed for themes. The following discussion includes both a description of the sample and of three emergent themes.

#### **Description of the Sample**

The research sample consisted of 27 adult participants who have been legally blind since early childhood. I conducted interviews with participants who were located in the United States, Canada, and England.

There were 19 females who ranged in age from 28–70, with a mean age of 51. Sixteen identified as Caucasian, two identified as Hispanic, and one reported she was born in the Philippines and was adopted by a Caucasian family. There were eight males who ranged in age from 29–75, with a mean age of 48. Four identified as Caucasian, two identified as African American, one identified as British, and one identified as French Canadian. The age range of all participants was 28–75, with a mean age of 50.

The participants were asked about their eye condition and visual impairment. Those who reported having no light perception from birth included five females and five males. Two females reported they were born with light perception only. Two females and one male reported having light perception in one eye and no light perception in the other eye from birth. One male reported being born legally blind in one eye and having no light perception in the other eye. Seven females and one male reported maintaining legal blindness across the lifespan. Three females reported

being born with progressive vision loss, starting with some functional vision and resulting in no light perception.

The education level of participants included four females with a high school diploma. Two females reported attending some college. Four females stated they received a Bachelor's degree. Nine females obtained a Master's degree. One male reported receiving a high school diploma. One male reported attending some college. One male reported obtaining an Associate's degree. Two males reported receiving their Bachelor's degree. Two males reported having a Master's degree. One male stated he earned a PhD. In total, five participants received a high school diploma, three attended some college, one obtained an Associate's degree, six received a Bachelor's degree, 11 earned a Master's degree, and one received a PhD.

The employment status of the female participants included six who reported being employed full-time. Four females said they were retired. One female reported working part-time. Three females stated they were self-employed. Five females reported being unemployed at the time of the interview.

Of the males, two reported being employed full-time. Two males reported working part-time. One male stated he was retired. One male reported being self-employed. Two males reported being unemployed. In total, eight participants reported full-time employment. Five participants said they were retired. Three participants stated they worked part-time. Four participants reported self-employment. Seven participants reported unemployment.

The income range for the female participants was \$20,000.00–\$125,000.00, with a mean of \$48,615.38. Three reported their annual income as Social Security Disability. One female who stated she worked full-time declined to report her income. One female reported her income from self-employment to be at the poverty level. One female who reported

unemployment stated she had no personal annual income at this time. Of the females who provided information regarding their annual income from full-time employment, one reported an annual income of \$20,000.00. One female reported an annual income of \$43,000.00. One female stated her annual income was \$46,000.00. One female reported an annual income of \$125,000.00. One female reported an annual income of \$50,000.00. The female who reported part-time employment stated her annual income was \$50,000.00. Three females who reported retirement stated their annual income was \$50,000.00. One retired female reported an annual income of \$60,000.00. One female reported her self-employment annual income to be \$30,000.00. Another female reported her annual income from self-employment as \$33,000.00. One female who stated she was unemployed reported receiving an annual income of \$25,000.00.

The income range for the male participants was \$15,000–\$250,000, with a mean of \$79,166.66. Two males reported their annual income to be from Social Security Disability. Of the males who reported full-time employment, one reported his annual income to be \$15,000.00, and the other reported an annual income of \$100,00.00. One male reported annual income from part-time employment as \$25,000.00. One male reported part-time annual income to be \$35,000.00. One male reported annual income from self-employment as \$50,000.00. One male reported annual income from retirement to be \$250,000.00. The income range for all participants was \$15,000.00 to \$250,000.00, with a mean of \$58,263.16.

Three females reported having no siblings. One female reported being the youngest in her family of origin with one brother 5 years older and one sister 8 years older. One female reported being the youngest in her family of origin, with a sister 2 years older and another sister 12 years older. One female reported being the youngest in her family of origin, with a brother 3.5 years older, as well as a half-brother 14 years older and a half-sister 16 years older.

One female reported being the third of four children in her family of origin, with one brother 23

years older, one sister 21 years older, and one sister 2.5 years younger. One female reported being the oldest in a blended family, with one sister 2.5 years younger who also has a visual impairment, one brother 6 years younger, a twin brother and sister 8 years younger, and a sister 8 years younger. One female reported having a half-sister 2 years older and a sister 2 years younger who also has a visual impairment. One female reported being the oldest of 7 children, having 4 brothers and 2 sisters ranging in age from 11 months to 7 years younger. One female reported having one brother and four sisters, ranging from 8 years older to 8 years younger than the participant. One female reported having a sister 4 years younger, as well as a half-sister 14 years younger and a half-brother 16 years younger. One female reported having a sister with a 2.5 year age difference. One female reported having a brother 18 months older. One female reported having a brother 1 year younger, one brother 22 years younger, and one sister 26 years younger. One female reported having a sister 11 years younger than her. One female reported having two sisters, one 10 years older and one 14 years older. One female reported having a twin sister who is also blind, as well as a 7.5 years younger brother. One female reported she was adopted and reported having one sister and one brother; no ages were provided.

One male reported being the oldest of 6 children in his family of origin, with three sisters, one brother, and a half-brother ranging in age from 1.5 years younger to 20 years younger. One male reported being the seventh of eight children, with five sisters and two brothers, ranging in age from 15 years older to 22 months younger. One male reported having a stepsister who is 2 years younger. One male reported having one brother 2 years older. One male reported having two brothers, one 18 months older and one 5 years younger. One male reported having three brothers and being the middle child. One male reported having five sisters, three older and two younger. One male reported having two older sisters.

## **Findings**

The purpose of this qualitative, retrospective study was to phenomenologically examine the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. To guide this study, I focused on the following question: What are the lived experiences of childhood play as reported by adults who have been legally blind since they were children? Of the participants, 23 were interviewed by telephone and four provided their responses to the interview via email. Participants were encouraged to speak openly and to elaborate as much as they felt comfortable doing so. On occasion, prompts and follow-up questions were asked in order to gain clarity on comments made by the participants.

I analyzed the data by listening to the audio recordings and rereading the interview transcripts multiple times. Two research assistants analyzed the same eight transcripts randomly chosen by the researcher, and the members of the research committee read a portion of the transcripts. The Dissertation Director and one committee member identified significant statements and themes that were consistent with those found by my research assistants and me. As participants spoke about their experiences of childhood play and blindness, three themes emerged. Verbatim quotes from participants are used to support the identified themes, which are: (1) Parental Attitude and Involvement, (2) Sibling Inclusion, and (3) Peer Isolation.

### **Parental Attitude and Involvement**

Parental attitude and involvement was the first theme that emerged from the data. Parten (1932) encouraged parents to begin playing with children at an early age. Several participants in this study attributed their feelings toward play to their parents and family. The results also clearly link parental attitude and involvement with play, self-advocacy, and development across the lifespan. Some participants reported their parents took the time to learn to read and write Braille, which leveled the playing field for communication. Some participants stated their

parents took time out to enhance their conceptual development by bringing the visual world to them in nonvisual ways, which included providing frames of reference for real-world objects and experiences. Several participants also reported learning independent living skills from their parents, such as cooking, cleaning, and doing yardwork through play. One participant said her mother and grandmother made a competition out of shelling peas and beans. The participant reported being the one to check all their pans to see who shelled the most. She said she always tried her hardest to win by focusing on the sound each person made when shelling and dropping the peas and beans into the pans. Most participants reported that parents and family members provided encouragement for their interests and taught them to embrace who they are. Several participants stated their parents modeled adaptation by how quickly they appeared to adjust to their child's vision loss and treat them as they would any other member of the family. This section illustrates the various ways in which participants describe parental attitude and involvement as it relates to blindness, play, and development across the lifespan.

“My mom was determined that I would be normal.” (Participant 14F)

“I was fortunate to live with parents who really were engaged.” (Participant 17M)

I learned to ride my tricycle when I was two. I loved riding it, and I was riding actually on ice, because it was icy that winter, and they just put it out there and said, you know, “Here you go.” So, my parents, although they were watching me all the time, they just let me do whatever it was I felt like I could do. (Participant 02F)

Somehow, they knew how to raise a blind child correctly because once they realized that I couldn't see, they just said, “Okay. We're just going to raise her like we are the other girls,” and they did. And so, they would ask me questions about, “Can you see this or that?” You know, something. And if I said I could see it, which I never lied about, I never tried to make them feel better by lying like some people might do, they would be excited

and go, “Wow, that’s great you can see that!” And if I said no, they would say, “Well, here. Let’s touch it then.” they would take me all kinds of places to let me touch everything under the sun. So, I always knew that I was blind. I always knew that I couldn’t see because my parents really spoke about it. (Participant 02F)

My parents would say, “If you can’t do something, you’re going to do it until you can. “So, they never stopped me, they never said, okay, you’re legally blind and you can’t do this, they never did that, they never ever did it. My mom would pick something that I had a hard time with, like folding a towel perfectly, and an hour a day I would stay until I could do it. And then once I could do it, then we moved on to the next task and then at the end of the week, she would have me redo it so that she could make sure that I knew how to do it. And that translates to now because I’ll keep on practicing until I get it right. So, my family just played a huge part in teaching me all the things that I needed to know to – well, I guess they figured I was already gonna have a hard time so they were gonna do as much as they could to make sure that I fit in the best that I could. (Participant 20F)

I grew up in a small town, and my family didn’t have any connection with other blind people. And they didn’t really know what to do with me. And so, pretty early, we started hearing things from the public school system, like there are special schools for your blind daughter. And my family didn’t really want anything to do with that. Probably one of the biggest gifts my family gave me, and they did it for the wrong reasons, because appearance was really important to them. I mean, overly important to them. Too important. But the good news about that was, I learned to be appropriate. I learned to put my hand out when meeting people. I learned to face them when I spoke to them. I never had trouble with facial expressions. I knew how to stand straight. I wasn’t allowed to rock. You know that rocking? I wasn’t allowed. That stopped. My family stopped me



from doing that. We had a whole system. Same with putting my fingers in my eyes. I don't do that. I learned to put my head up when I was talking to people. And not to – And also to pay attention to what they were talking about. Even if I couldn't totally participate from experience. And the one thing that always disturbs me, is that now, these days, kids are allowed to do things that I never would have been allowed to do. If they're inappropriate, if they talk too loud, or they're talking over people, or if they're twisting and turning and shaking their heads, all of that's accepted now. Oh, well, you know, that's okay. No, it's not. It's not okay, and people need to learn that advocating for yourself doesn't mean that the world is going to accommodate you, especially if what you're doing is not, quote, normal. (Participant 15F)

There were things that my parents did adapt for us a little bit. Board games especially. Board games I feel like are play as well. But those my mom would glue, and we were able to follow it. And when (Two Names Deleted) got older, they were able to read it to us. My mom tried to Braille as much as she could. Oh yeah. My mom knows Braille. She learned to read and write it, and then she also would transcribe Braille a lot. Like she would volunteer for the school district, and so we actually had an embosser at home.” (Participant 07F)

Well, of course when I got a little older, we started on the board games. And my parents would play board games with me. And Mother would make the boards – she'd braille the boards where I could use them. And I wouldn't just roll the dice and they would move me. I'd get to move myself and stuff like that. My mom went out and learned braille when I was born and came back and taught it to me. (Participant 11M)

My mom presented me with a transistor radio, which was a head, a face with the volume knob and the – turning the dials up, being the eyes and the face and the speaker being the hair. (Participant 09F)

When we would take vacations, my mom, if we'd go see like a monument, like a national monument or something, my mom would get a replica of it. So like I have a replica of what the Lincoln Memorial looks like because we went to it, but I couldn't see it because it's white on white background. So my mom bought one, and getting my hands on that gave me a better understanding of what the Lincoln Memorial looked like. Because I'm just picturing this little tiny dude in this little tiny chair. (Participant 07F)

Oh, my mom thought way outside the box for everything. You know, she was all about that. And my cousins didn't care. They were like, "You're blind? I don't care. You're getting pushed off the trampoline just like everybody else does. (Participant 07F)

### **Sibling Inclusion**

Sibling relationships can be impacted when one or more children have disabilities (Howe, 2006). While sibling relationships across the board vary and depend on numerous factors, blindness can be a significant determinant in whether siblings form strong bonds or develop resentment. The participants in this study who reported on aspects of their relationships with siblings are no different. The results varied. Most participants reported having close sibling relationships and were included in activities with their siblings. In fact, three participants have a sibling who is also blind. One participant said she and her twin did not even realize they were blind until they were around 5 years old. One participant reported having a wonderful relationship with her younger sister who is also blind. However, she reported not being close with her older sister who is not visually impaired. This section describes the ways in which blindness and visual impairment affected sibling relationships across the lifespan.

My sister could see. And so, she would provide all this narration if we were playing together. She would say, “Oh, the waves are so high!” And then she would go, “Whoosh!” And she would tell me to make the sounds that she made. And so, she had a lot to do with, I guess, probably forming some of my first ideas of what things sounded like. (Participant 02F)

I also was very fortunate because my brother, who was 3 years older than myself, after I got to be about 3 myself, when neighborhood kids would come and want to play, he would almost always say, “Well, I’ll play if there’s something she can do, too.” (Participant 03F)

I don’t remember a lot of play with like friends, per se. But with my siblings and with my cousins, the messages that I received in terms of how I played, it was just that they just – I can’t think of a specific message that I got out of it, it was just what we did. You know? And my cousins – I guess because they didn’t treat me any differently, I got the message that I wasn’t any different. My siblings and I are very close now, and I think it’s because we played so much as children, and we spent so much time together. (Participant 07F)

My sister and I would play dolls together. We would – just whatever she was into, she was always taking me with her, wherever we were. My brother came along not too long after that, so we would invent games, we would – like one of us would grab the hands by the head and the other one would grab the feet and we would like swing each other. We would – you know there were times when I would be the person swung and sometimes, I’d be the person swinging. And I think that’s because they didn’t have a chance to think about, oh, no, I’m just one blind child. It’s everybody and we were all included.

(Participant 09F)

Play was really fun. If I think back, it was fun; it was normal, I didn't get left out. I was part of everything that my cousins did so that's the only way I can think about it, it was fun, I loved them. Even with my brother, when it was just me and my brother, we had fun. I owe my family a lot because they – number one we're family supportive and number two, I never got shunned by any of the kids – any of my cousins or my brothers or sisters, I never got shunned. (Participant 20F)

The younger sister I grew up with, she was always my, "Look after (04)" kind of person, you know? "Go play and go have fun, but keep an eye on your sister." That kind of thing. So, it wasn't a me keep an eye on her, it was a her keep an eye on me, and that sort of thing. And I know, because she's told me this, that there was quite a lot of resentment when that sort of thing would happen. And she and I don't get on well now at all.

(Participant 04F)

And then my older sister was generally critical of everything I did. But it would be about anything from you only have book smarts, not street smarts, you dress dumb, you do this, you do that. And ironically, she was nice to my little sister, who did many of the same things. So, I don't know what the deal was there. (Participant 08F)

My sister and I didn't ever play much. She and I were kind of in different circles, and different orbits. And so, we were not close. I think, frankly, it was probably hard for her to be my sister, because she was older than I, and yet I was kind of the kid who got the attention. Not within my family, but in school. Like, when I was Snow White, she was a tree. (Participant 15F)

## Peer Isolation

Peer isolation and bullying can occur with any type of difference. However, blindness presents a fear factor that tends to exceed that of most any targeted characteristic (Dutton & Lueck, 2015). Children who are blind tend to be excluded from play and social activities for various reasons, including activities not being modified or adapted, the perception that the child who is blind is slower than everyone else and would not be able to keep up, and others' feelings of discomfort or awkwardness around blindness. Children who are blind may have difficulty locating peers, as well as extricating themselves from a situation, making it easy for bullies to target them.

Most participants in this study reported some sort of peer isolation and bullying as children, as well as being held back and excluded from activities due to adults' fears, discomfort, and inappropriate ways of providing necessary feedback. One participant reported that his father encouraged him to have the training wheels taken off his bike. He stated the teachers made a point to let his father know how cruel he was being to the participant. One participant stated that while at boarding school with other children with visual impairments, he was called out by a teacher in front of the entire class when he had difficulty with mastering both travel and independent living skills. He also reported that the other students joined in, and the teacher let it happen. One participant reported that she and her family attributed difficulties to a learning disability and did not realize she had a diagnosis of legal blindness until adulthood, which made it even more difficult to participate in social situations as a child. Multiple participants stated that their limited peer inclusion led to a lag in the ability to discern nonverbal social cues, understand sarcasm, and pick up on nonverbal expressions of emotion. Most participants reported inclusion among family members and not realizing something was different about them until they went to school. A few participants reported growing up in small

towns and within tight-knit communities where bullying and peer isolation seldom occurred.

This section includes descriptions of participants' experiences with both peers and adults.

It wasn't like, "Yeah, go play with your friends," until I was in maybe middle school. And then I was allowed to ride my bike with my little sister, but I was never alone. Because it was always like, "Don't let [04] fall." "Don't let [04] play contact sports." (Participant 04F)

Just like when you try for jobs. I retired from the agency after 23 years. But that wasn't my dream job. I wanted to do something really important. But that ended up being really important, but I didn't think it was until I actually did it. And so, I've just – I tried to get into personnel in the oil field and some other things. I just could never get anybody to give me a chance. And when people had to put their money down or rely on your recommend, they wouldn't do it. (Participant 11M)

I never felt that I could participate in art class because I remember one time when I made something, we were supposed to be gluing some tile on some kind of little thing. We were gluing the tile, and I just put them all lined up together – like a floor tile – and I thought, "Wow, they're in a row just like tiles on the floor. Don't they look neat?" and the teacher told me "It looks really terrible." This really happened. I don't know that she meant it as mean as it was because I kinda felt like I don't wanna do this then. I just don't wanna do it. I don't ever wanna do it. I hate this. So, I still have that feeling, "Don't you wanna be creative?", "No, I don't wanna be creative. Go away." So, with music, it might be different. Even with music though, I never really improvised very much. I think I had a fear that I just could not overcome. Being seen without me being able to see back, and then when people laugh at me. I never felt like I was upset about not being able to see, yet I went through that at some point. But that's not what this was about though. It was more

they had something over me, and they'd never laugh at me, and I'd just wanna get away. That's why I used to go and play by myself, and I played with dolls until pretty late. But then, I kinda played with dolls in my own strange way. And a lot of it, I did alone. But sometimes I would get upset because the other kids didn't wanna play with me. I remember that happening too, that sometimes I just didn't wanna participate. (Participant 13F)

Well, I think it's good that they include you in public schools, but in terms of play and stuff, I got excluded a lot in school and the teachers didn't wanna be bothered, like they would push me aside because they didn't wanna have to do the extra work that it took, but the one thing, and you touched on it in your podcast too, from little, I was actually able to advocate for myself, like I have no problem speaking up. But when I got to play the Goalball, when the sports were adapted for the blind, it felt so good because then I wasn't the outcast. Public school is very hard because I always felt like the outcast, even though I had to advocate for myself, I always felt like I was always fighting, fighting for teachers to help me; fighting for – because I only had – it was regular public school and then it had a VI class that you went to, to get notes brailled or if you needed help with something, but – so it was good that – but then I look at people who went to schools for the blind and for me, I feel like they got a better education. I don't know, there are so many benefits to being in a school for the blind because you feel like you fit in, but then in some cases, you don't know how to advocate for yourself and stuff. I don't know because I've been in, like I said, I've been – my toughest time was public school, just trying to get an education, but I did know how to advocate for myself because of my family. (Participant 20F)

Most of my feedback and most of my play was done with my siblings or my cousins. I was bullied as a child, badly, so I really didn't – I had some friends in elementary school. Early, early second, third grade elementary school. And I remember them coming over to the house a couple of times like for a slumber party and playing like with Furbies. But I don't have a lot of memories of actually playing like on a playground with other children that weren't my family. There was a rumor that was spread that I was blind, and blindness was contagious, and so nobody wanted to hang out with me. And that stopped for a few years until I left that elementary school. (Participant 07F)

At school was when I noticed the most difference because at school a lot of the games were set for people who could see. So, you know we had basketball, we had tetherball, we had dodgeball, we had – it was partner games. And I think that as I noticed that I was not included as much as I could have been or should have been. I think play had a big deal in the way that I developed language-wise, communicating with people, being part of a team, playing. I wish that more could have been done in school. But I think that's so key for kids. I think that they need to be included in teams, they need to be included as part of something, they need to feel like – like they are a part of something. And I think that when they go to schools for the blind where they're segregated into such things, then like they do cheerleading, they do athletics, they do different things that makes them like regular kids. (Participant 09F)

I mean there was one kid who tied my shoes together. There were kids who would throw balls at my head and claim it was an accident and they would knock me out. (Participant 08F)

Yeah. I mean I know I look different and I've spent my whole life having to be different and having to deal with the repercussions of that. And sometimes like after a week like



this week at work where I'm like I'm tired of being different, I have to remember the ways in which I'm proud of or happy with or okay with being different. You know the repercussions of being different. People resenting, me not being able to keep up, and so it's constantly thrown in my face, you're different, you're different, you're different. And maybe it's just that they're all the same. So, but it can get you down after a while, even when you're resilient, even when you're forceful, even when you're adaptable. And when you finally lose it, they're like, you just have to be adaptable, you just have to be positive. And it's like, I'm about had it up to here with being adaptable. And so sometimes I kind of go off into that place of play or that place of sometimes now it's the place of creating or the place of doing art or whatever. That's still play to me. And that's kind of how I retain this is how I'm okay being different. (Participant 08F)

### **Summary**

This chapter presented the results of a qualitative, phenomenological, and retrospective study that explored the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. Semi-structured interviews were conducted with 27 participants who agreed to participate in the study. Demographic information, three emergent themes, and verbatim quotes from the participants to illustrate each theme were included. The analysis of the data brought forth three themes: (1) parental attitude and involvement, (2) sibling inclusion, and (3) peer isolation.

CHAPTER V  
DISCUSSION, CONCLUSIONS, IMPLICATIONS, LIMITATIONS, AND  
RECOMMENDATIONS

The purpose of this qualitative, retrospective, phenomenological study was to explore the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. Both family systems and sociocultural theories were used as a lens through which each participant's unique experience could be viewed. A phenomenological approach allowed me to capture the meaning each participant made of their experiences with childhood play. Semi-structured interviews were conducted with the 27 participants. Each participant was asked to respond to the following nine interview questions:

- (1) Please tell me what you remember about play from when you were a child.
- (2) How did you play as a child?
- (3) Please describe any impact your blindness may have had on the ways in which you played.
- (4) Please describe the feedback and messages you received from friends, family members, teachers, caregivers, and others about how you played as a child.
- (5) How did the ways in which you played change as you became older?
- (6) Please describe the value and importance of play within your family and culture both as a child and as an adult.
- (7) What do you wish you had learned about play as a child?
- (8) Based on your experiences, what would you like for children who are blind to know about play?

(9) What advice about playing with children who are blind would you give to caregivers, service providers, siblings, and peers?

Answers were occasionally followed up with prompts and questions to clarify meaning. All transcripts were read multiple times, and the data were analyzed for themes. This chapter provides a discussion of the results, reviews conclusions and implications of the findings, discusses research limitations, and offers recommendations for future research.

### **Discussion**

The following section includes an expansion of the 3 emergent themes as the findings relate to previous research on play and blindness.

Previous research has illustrated the difficulties children who are blind have when it comes to play (Dominguez & Dominguez, 1991; Sacks & Wolffe, 2006). The authors of these studies included statements from children and adolescents who were blind at the time which indicated negative connotations of what play meant to them. The qualitative research study I conducted offered the adult participants to speak openly about their experiences of childhood play from when they were children with a diagnosis of legal blindness. Only two participants reported that the word play had negative connotations for them. However, they reported continuing to engage in recreational activities, without associating the word play with what they are doing. These participants stated that the word play made them think of forced interactions during activities in which they did not want to participate.

In contrast, the rest of the participants reported having extremely positive memories of childhood play. They described play as fun, laughter, bonding, quality time, creative, learning, and escaping to another place, just for a while. One participant stated that play helps people not take themselves so seriously. She said that people can find humor in most anything that happens, if they just look for it. For some, play involved sports, but this was not the case for most

participants. However, most all participants stated that making sure children who are blind get to experience being on teams and working together is paramount for success as an adult. Roe (2008) echoed these same sentiments and stated that the more children who are blind have an opportunity to be involved in both group and team activities, the more likely they are to display self-confidence, accept constructive criticism, and excel in the workplace as adults.

Play can provide a safe and natural environment for experiencing and experimenting with new concepts in order to build self-confidence (Parten, 1932). Vygotsky (1978) theorized that children enhance their problem-solving skills through imaginative play. For instance, children in preschool lay the foundation for abstract thinking by developing the ability to conceptualize events and objects that are not within reach. By depending less on tangible props and engaging in complex pretend play, children learn emotional self-regulation, as well as develop the ability to incorporate figurative language and thoughts into their worldview. When asked about how they played as a child, more than half of the participants spoke to the importance of imagination and pretend play. About half of these participants had imaginary friends until they were in late elementary school. For the participants in this study, pretend play centered around functional and sociodramatic play. Tröster and Brambring (1994) urged parents and educators of children who are blind to keep play actions similar to reality. About two-thirds of the participants reported writing and making up stories, reenacting scenes from movies and television, role-playing with friends and family, and using objects such as dolls to tell stories.

A high importance was placed on developing sequential, episodic memory through play. Jacko et al., (2013) postulated that by using play to develop sequential memory, children who are blind are better able to understand their experiences and relate them to new ones, since they do not have a visual frame of reference. About one-third of the participants stated they played games with siblings and friends, such as pretending they were in an elevator, playing school,

house, daycare, grocery store, and working in professional settings. About one-fourth of the participants reported engaging in typical early childhood play activities, such as running, jumping, climbing, and swinging. Less than half of these participants reported riding tricycles and bicycles.

Sacks and Wolffe (2006) pointed out that children who are blind may be delayed in developing play skills. These children face numerous social challenges (Dutton & Lueck, 2015; Zihl & Dutton, 2015). They may have difficulty locating toys, finding a friend on the playground, reading facial expressions, and moving freely in play areas (Roe, 2008). Over three-fourths of the participants reported engaging in solo play for the majority of their play activities. Over half of the participants reported having difficulty playing with peers during recess. They claimed to retreat into books or sit alone until it was time to go inside.

Preisler (1993) claimed that children who are blind typically engage in more exploratory play than pretend play. Tröster and Brambring (1994) found that the primary differences in how children who are blind play compared to their sighted peers were that children who are sighted tend to develop more complex play skills at an earlier age, sighted children interact with other peers more frequently, and children who are blind prefer tactile and auditory toys to symbolic games. Some participants reported enjoying parallel play, but most participants discussed daydreaming and being in their head.

Almost all participants reported enjoying music, making up sounds and words, recording themselves and others, and playing games, both alone and with others. Some participants reported fixating on various sounds. One participant reported wanting (and receiving) a roll of foil for her birthday. Others reported being afraid of and having aversions to certain sounds and textures.

As participants grew older, they reported changes in the ways in which they played. Most said that they grew out of imaginary play, which is typical for most children (Gilpin et al., 2015). Preferred activities included hanging out with friends, roller skating, reading, playing cards, board games, computer games, and going to the movies.

When asked about the impact their blindness may have had on the ways in which they played, about one-fourth of the participants reported blindness was not a factor. One participant said that because of her blindness, she did not venture off by herself in the same ways she did when other children were around. Others reported that blindness mostly impacted the treatment they received from peers and other adults.

Participants were asked to reflect on the value and importance of play in their family and culture, both as a child and as an adult. Most participants reported play was and is still valued highly in their lives. One participant reported that play was an expression of love and how her family spent quality time together. She also stated that play is important for learning about one's culture and for being set up for success as an adult. Almost all participants mentioned that play is vital for learning skills like sharing, cooperation, and compromise. Some participants reported that play is valuable for learning how to explore and learn creativity by pretending to be different people and objects. Most participants claimed that play continues to be of high value as an adult.

Participants were asked about any feedback they received from caregivers, siblings, service providers, and peers about the ways in which they played. Most of this information was reported in the emergent theme of peer isolation. However, most all participants reported receiving encouragement from family and having friends and mentors during adolescence who helped them along the way. One participant reported that she had an older friend who helped her with crafts at Vacation Bible School. Instead of doing the craft for her, the participant reported

her friend was patient and helped her so that she could complete the project herself. Other participants stated that their adverse experiences with peers helped them to become better self-advocates later in life.

Participants were asked if there was anything they wish they had known about play as a child. About three-fourths of the participants reported they felt they received everything they could from their experiences with play. About half of the participants reported wishing for more experience playing with toys that increase motor skill development, as well as having better motor skills in general. Six participants specifically mentioned wishing they could have understood better how to play more creatively with clay and Playdough. One participant said she wished she could have kept up with others and to have known that everyone can be included in play. Of the participants, 17 mentioned wishing they had a better understanding of facial expressions, gestures, and nonverbal social cues. One participant said that she would have liked to have learned how to smile for photographs. Most participants stated they wished they had more realistic, functional toys that emulated real-world objects, in order to understand conceptual aspects that are missed without being able to see.

Participants were asked to provide any advice to children who are blind in terms of play. The overarching advice given was to “just do it.” Almost all participants wanted children who are blind to push the envelope, explore, learn how to advocate for their needs, and to use their imagination.

Participants were asked to wrap up the interview with any advice they would give to caregivers, siblings, peers, and service providers about playing with blind children. The overarching advice for caregivers and the like was to let the child who is blind explore and to treat them like any other child without shaming them for engaging in blindisms. Participants stated that the child who is blind should not be the one making adaptations all of the time.

Caregivers, siblings, and service providers should embrace the child's creativity, allow ample questions, and provide specific feedback on social cues.

The participants' responses to the interview questions illustrate how both family systems and sociocultural theories played a dynamic role in the development of the participants and the ways in which they perceive play (Bowen, 1978; Vygotsky, 1978). Both theories discussed the importance of interdependence, finding a balance between performing tasks individually and giving and receiving aid to one another when needed. Family systems theory focuses on how patterns dictate events (Bowen, 1978; Hanson, 1995). Sociocultural theory claims that meeting children at their zone of proximal development and providing scaffolding to help children develop more advanced problem-solving skills increases their ability to perform more complex tasks, which in turn increases self-confidence (Bruner, 1961; Vygotsky, 1967; Vygotsky, 1978). It is apparent that most of the participants in this study were encouraged to become interdependent and received scaffolding from their families of origin that allowed them to embrace their own creativity and unique perspectives, in spite of adversity they may have experienced when navigating the social world as children.

### **Conclusions**

A phenomenological research approach was used to capture the lived experiences of childhood play as reported by 27 adults who have been legally blind since they were children. These retrospective accounts provided a glimpse into each participant's life, especially in terms of the systemic and sociocultural aspects of the role of play and its effects across the lifespan. The participants' childhood play experiences were overwhelmingly positive. Most reported having fond memories of play and spoke to its continued value in their lives.

Parental attitude and involvement, sibling inclusion, and peer isolation were the three emergent themes extrapolated from the data. Parents who worked through their own adjustment



to blindness, treated their child as equally as other siblings, were encouraging, had high but realistic expectations, and accepted blindness, aided their children in their ability to learn through play and have typical play experiences. Parents who stretched their own skills by learning Braille, met their child where they were, took time to provide in-depth explanations of objects and experiences, sought assistance, advocated for their child's needs, and did not sit back in the shadows, aided their children in being able to develop through play. Siblings who were not asked to take on caregiving responsibilities for their sibling who is blind, did not use blindness as a barrier, included the sibling who is blind in play, and treated their sibling like typical siblings do by correcting social mistakes and giving feedback allowed for more bonding opportunities and closer relationships. Participants reported tight-knit families and inclusive relatives, but most reported vastly different experiences at school with peers, as well as with teachers in some cases. This is the area in which participants reported lacking social skills development.

It is apparent from the results and the discussion of the findings that this study corroborates previous research on play and blindness. Campbell (2007) spoke to the importance of providing commentary and visual frames of references in order for children who are blind to understand emotional expression. Roe (2008) urged service providers and caregivers to encourage peers to provide appropriate social feedback. All participants encouraged children who are blind to engage in more exploration, advocate for their needs, and to take calculated risks. The participants also advised caregivers and service providers not to hold back children who are blind, based on their own fear and discomfort.

Previous research on play and blindness reported preferences for solo, parallel, and functional play, with little to no emphasis on symbolic play (Dominguez & Dominguez, 1991; Sacks & Wolffe, 2006). The participants reported similar leanings. Overall, participants

preferred to play alone for the most part and engaged in more functional and sociodramatic play. Several participants reported fixating on sounds as children, as well as preferring play activities that differed from sighted peers in the same age group. At times, such vast differences in preferred play activities contributed to peer isolation, as also reported by Preisler (1993). However, the participants in this study chose to focus on the positive aspects of their struggles. They discussed becoming more resilient by overcoming adversity. Overall, the results from this study show that while there are specific issues concerning development related to blindness, children who are blind experience play in the same ways as their sighted peers.

### **Implications**

The results of this study appear to corroborate previous research on play and blindness. However, this information is potentially new for most marriage and family therapists. Based on the information provided by the participants, there are multiple avenues for therapists to play an integral and systemic role in the lives of children who are blind and their families, helping them navigate through the adjustment process.

Therapists can help by recognizing that while some blindisms may be similar to characteristics of autism, it is important not to quickly jump to adding that diagnosis. They can work with the family to find appropriate ways for the child to receive certain sensory input that are not either physically or emotionally harmful, such as offering time on a swing as a reward for not rocking while standing in a public place. Additionally, they can work with parents to provide feedback that does not shame the child. Therapists can help parents learn and enhance their advocacy skills, while also working with the child to understand how to speak up for their own needs. Therapists can help parents understand the value of play, especially for teaching children who are blind about the visual world around them. Therapists are encouraged to take a deep dive into learning the differences between grief and chronic sorrow, as the features of

chronic sorrow more accurately explain the process parents and family members go through when coping with a child's vision loss.

### **Limitations**

There are limitations to this research. For the most part, the participants belong to a homogenous group. They largely have similar educational backgrounds and levels of income that are higher than the general population of people who are blind and visually impaired (Bell & Mino, 2015). Of the 27 participants, 20 are Caucasian, thus underrepresenting most racial and ethnic groups. The homogeneity of the participants may have had an effect on how the participants answered the interview questions in terms of parental and sibling involvement, which may not be an accurate representation of the population as a whole. Furthermore, the accounts were provided by people well into adulthood. Their memories of situations and events either may be less accurate than during childhood or have been slightly altered by changes in perspective from childhood to adulthood.

The sample of participants was not randomly selected. Both purposive and snowball sampling were used during recruitment. Moreover, I knew 13 out of the 27 participants prior to the beginning of the study, which could have affected how the participants chose to answer the interview questions. Finally, I am also a part of the blind community. This may have had an effect on the outcome of the study. Even though I made every effort to bracket, stay neutral, and suspend my own biases, the results are not objective due to the nature of qualitative, phenomenological research. That being said, the lived experiences of the participants provide unique perspectives that may not be offered based on other research methods.

### **Recommendations**

This study has added to the limited body of literature on the lived experiences of childhood play as reported by adults who have been legally blind since they were children.

However, additional research would serve to broaden the field and benefit mental health professionals and other service providers who may work with families who have a child who is blind. First of all, it would be helpful to better educate therapists and service providers on blindness and its effects on development, in order to continue increasing awareness and reducing stigma around vision loss. This could be done through university classes, continuing education workshops, and through practicum opportunities that would expose therapists and service providers to more people who are blind.

Second, it could be helpful to conduct similar research by separating out participants who have some vision from those who are totally blind. Even though all participants in this study were legally blind, those with some vision still had a modicum of a visual frame of reference that could have potentially skewed the data.

Third, conducting research on play and development with children who are blind would expand the body of knowledge with real-time results on current play preferences, as well as effects on familial and peer relationships. Perhaps a longitudinal study would provide depth and breadth into the linkage of play and development across the lifespan, as it relates to blindness and visual impairment.

Finally, it is recommended that similar research is conducted on participants with more diverse backgrounds. This study did not fully represent the general population of people who are blind and visually impaired. Diversifying the sample would provide more accurate information for therapists and service providers in terms of curriculum and program development, as well as maximizing services for children who are blind and their families.

### **Summary**

The purpose of this qualitative, retrospective, phenomenological study was to explore the lived experiences of childhood play as reported by 27 adults who have been legally blind since

they were children. Both family systems and sociocultural theories were used as a lens through which each participant's unique experience could be viewed. A phenomenological approach allowed me to capture the meaning each participant made of their experiences with childhood play. This chapter provided a discussion of the three emergent themes and reviewed conclusions drawn from the findings. Implications and limitations of the research were discussed. Recommendations were made for family therapists and service providers, as well as for future research. This retrospective data serves to broaden our knowledge and understanding of the targeted population, as well as invites continued research to explore the current needs of children who are blind.

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APPENDIX A

Recruitment Letter

What was play like for you as a child growing up legally blind? Here's your chance to tell your story.

Are you at least eighteen years of age? Are you legally blind? Do you want the chance to have an impact on the lives of children who are blind? If so, you are invited to participate in a research study about play. My name is Janice Moran, and I am currently a PhD Candidate in family therapy at Texas Woman's University (TWU.)

I am speaking with adults who are blind and asking questions about what it was like to play as a child. I will be talking with each person by telephone, because it is easier for people like us with visual impairments not to have to worry about arranging transportation. Yes, that's right. I said "people like us." I have been totally blind since birth and have an interest in making sure that children who are blind are able to have as many opportunities available to them as possible.

Your participation is voluntary. If you like, you may receive a summary of the results once the study has been completed. Are you ready to chat? Still not sure? Either way, please feel free to contact me for more information by either of the methods listed at the bottom of this letter.

*There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings, and internet transactions.* I appreciate your participation in this research study. Want to know more? Think you might be interested? Please feel free to email me at:

Principal Investigator

Research Advisor

Janice A. Moran

Linda Brock, Ph.D.

jamoran@mail.twu.edu

lbrock@mail.twu.edu

(214)394-2091

(940)898-2713

Thank You.

Sincerely,

Janice A. Moran

Linda Brock

APPENDIX B

Consent Form

TEXAS WOMAN’S UNIVERSITY  
CONSENT TO PARTICIPATE IN RESEARCH

Title: The Lived Experience of Childhood Play: Retrospective Accounts As Reported By  
Adults Who Have Been Legally Blind Since They Were Children

Investigator: Janice A. Moran.....jamoran@twu.edu 214/394-2091

Research Advisor: Linda Brock, PhD.....lbrock@twu.edu 940/898-2713

Key Information

You are being asked to participate in a research study at Texas Woman’s University. The purpose of this research is to explore the lived experience of childhood play as reported by adults who have been legally blind since they were children. You have been asked to participate in this study because you are an adult who identifies as legally blind. The investigator is a PhD Candidate in the Family Therapy program at Texas Woman’s University, and she has been totally blind since birth. The researcher will interview all participants by telephone. The researcher will also debrief with all participants by telephone. Both the interview and debriefing calls are expected to last for one hour. The total expected time commitment is two hours. All interviews and follow-up calls will be recorded. In order to be a participant in this study, you must be at least 18 years of age and identify as legally blind. Potential risks include discomfort with the questions being asked, as well as loss of confidentiality.



### Description of Procedures

As a participant in this study, you will be asked to complete an interview with the researcher and participate in a follow-up debriefing with the researcher, both by telephone. Each call will last approximately one hour, with an expected total time commitment of two hours. Both the interview and follow-up call will be recorded to ensure an accurate account of participants' stories. Only the researcher will have access to the recordings. Your interview will be assigned a numeric code to ensure confidentiality. The researcher will ask you questions about how you played as a child, messages you may have received from others about how you played, and how play may have impacted your adult life. In order to be a participant in this study, you must be at least 18 years of age and identify as legally blind.

### Potential Risks

The researcher will ask you questions about your experiences during different types of play as a child. A possible risk in this study is discomfort with the questions you are asked. If you become tired or upset you may take breaks as needed. You may also stop answering questions at any time and end the interview. The researcher will provide you with a list of counseling resources, should you wish to speak with a professional.

Another risk in this study is loss of confidentiality. Confidentiality will be protected to the extent that is allowed by law. *There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings, and internet transactions.* The electronic data will be encrypted and password protected. Only the researcher, her dissertation chair, and two research assistants will have access to any data collected. Research assistants will only have access to interview transcripts for coding purposes. The data will be destroyed within one year after the

study is finished. The results of the study will be reported in scientific magazines or journals, but your name or any other identifying information will not be included. Identifiers will be removed from the identifiable private information. After such removal, the information could be used for future research studies or distributed to another investigator for future research studies without additional informed consent from the subject or the legally authorized participant.

If you would like to participate in the current study but not allow your de-identified data to be used for future research, please initial here \_\_\_\_\_.

The researchers will try to prevent any problem that could happen because of this research. You should let the researchers know at once if there is a problem and they will help you. However, 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 study is completely voluntary and you may withdraw from the study at any time. No direct benefits will be provided to participants. However, following the completion of the study you may receive a summary of the results. If you would like to know the results of this study we will send them to you. Generalizable benefits include further knowledge in both family therapy and for the provision of services to children who are blind.\*

### Questions Regarding the Study

You will be asked to type your name in the space below and return the form to the researcher by email. Your electronic signature is as legally binding as if it were hand-written. 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 by e-mail at [IRB@mail.twu.edu](mailto:IRB@mail.twu.edu).

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Signature of Participant \_\_\_\_\_ Date \_\_\_\_\_

\*If you would like to know the results of this study tell us where you want them to be sent:

Email: \_\_\_\_\_

or

Address:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## APPENDIX C

### Demographic Information

The researcher will orally ask the demographic questions at the beginning of the interview.

Name:

Age As of Your Last Birthday:

Gender You Identify With:

Age of Onset of Blindness:

Eye Condition:

Highest Level of Education:

Number of Siblings:

Gender of Siblings:

Age Differences Between You and Your Siblings:

## APPENDIX D

### Initial Telephone/Email Script

“Hello, my name is Janice Moran. Thank you for responding to my flyer. I am a doctoral candidate in Family Therapy at Texas Woman's University where I am completing my degree. Not a lot is known about how childhood play impacts development across the lifespan regarding people who are blind, so I've chosen this topic to study.”

"The purpose of my research is to explore the experiences of childhood play as reported by adults who are legally blind. I am very interested to hear your story. If you agree to participate, I will interview you by telephone at a time that is convenient for you. The interview will last for about an hour. Please electronically sign the attached consent form and return it back to me by email. When we talk, I'll go over the consent form, collect some background information, and then begin the interview. Our conversation will be recorded so that I'll be able to accurately describe your experiences.”

“I'll use a code number to protect your confidentiality, and I'll be the only one to know your name. Your participation is completely voluntary, and you may withdraw at any time without penalty to you. *There is a potential risk of loss of confidentiality in all email, downloading, electronic meetings, and internet transactions.*”

"What questions do you have so far?" (All questions will be answered by the researcher.)

"Would you like your story to be part of the study?" (If the potential participant says yes, a time and date for the interview will be scheduled.) "Thank you for your time. I look

forward to chatting with you on the date and at the time we've agreed upon." (The researcher will repeat the time and date.) (If the potential participant says no, she or he will be asked if they know of anyone who might be willing to be a part of the study.)

"Thank you for taking the time to talk with me. Do you know of someone else who might want to be a part of my study? If so, please feel free to pass along my contact information."



## APPENDIX E

### Interview Guide

"Thank you for agreeing to be a part of my study." (Pause) "The purpose of the study is to explore the lived experiences of childhood play as reported by adults who have been legally blind since childhood. Your participation is completely voluntary, and you may withdraw at any time without penalty. Do you have any questions about the study?"

(Pause)

"You may take as many breaks as you need, and we can stop the interview at any time you wish. I'll record our conversation for accuracy. I am turning on the recorder now."

(Pause)

"Before we begin, I would like to go over the consent form. Would you like for me to read it aloud?" (The researcher will do so if the participant says yes.) "Do you have any questions about the consent form?" (Pause)

"I'll begin by asking you some questions to gather background information. If anything I say or ask is unclear, please let me know. If you are uncomfortable answering any of my questions, please let me know that, too."

(Any questions from the participant will be answered by the researcher.) (The researcher will obtain demographic information that the participant is willing to provide. Upon completion, the researcher will begin asking the interview questions.)

"We're finished with the background information. We'll now move onto the interview questions. I encourage you to speak freely, openly, and elaborate as much as you are able. Please think back to when you were very young."

"Tell me what you remember about play from when you were a child." (Pause)

"How did you play as a child?" (Pause)

"Please describe any impact your blindness may have had on the ways in which you played." (Pause)

"How did the ways in which you played change as you became older?" (Pause)

"Please describe the value and importance of play within your family and culture both as a child and as an adult." (Pause)

"What do you wish you had learned about play as a child?" (Pause)

"Based on your experiences, what would you like for children who are blind to know about play?" (Pause)

"What advice about playing with children who are blind would you give to caregivers, service providers, siblings, and peers?" (Pause)

Prompts:

"What more can you say about that?" "M-hmm...I see." "How so?" "What more could you say about that?" "Let me see if I understand what you are saying." "What about that has changed over time?" "What else comes to mind?" "Anything else?" "What more would you like to add?"

"We're finished with the interview now. If it's ok, I'll be contacting you in a few days to see if you'd like to add more information. If so, please let me know how you would like for me to get in touch with you. If you've asked for summary results from this study, a copy will be sent to the address you've given me. Thank you so much for your time and for the information you've given."

APPENDIX F  
Counseling Resources

American Counseling Association (ACA) 800-347-6647 Find A Counselor:

<http://www.counseling.org/aca-community/learn-about-counseling/what-is-counseling>

American Association of Marriage and Family Therapy (AAMFT) Therapist Locator at

[www.aamft.org](http://www.aamft.org)

Counseling and Family Therapy Clinic Texas Woman's University 114 Woodcock Hall

Denton, Texas 76204 940- 898-2620 This clinic is open to the public. Hours of

Operation: Monday 12pm to 8pm, Tue. – Fri. 9am to 8pm, and Saturday 9am to 3pm.

APPENDIX G

Telephone Follow-Up Script

"Hello, this is Janice Moran. How are you? I am calling today to follow up with you about our interview and to ask if you have questions or if you would like to add more information to the interview." (Participant will be given time to respond.)

(If there are questions, the researcher will respond to them. If there are no questions, the researcher will say,) "Thank you very much for participating in my research study. If you requested a summary of the study results, you will receive them in the mail at the address you provided during the interview. Again, thank you so much for your time and for your participation."