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**THE OCCUPATIONAL LIVES OF INDIVIDUALS WITH VISUAL IMPAIRMENT**

**by  
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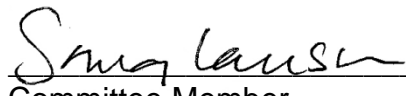
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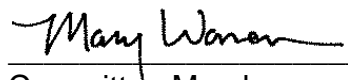
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## ABSTRACT

### **THE OCCUPATIONAL LIVES OF INDIVIDUALS WITH VISUAL IMPAIRMENT**

Julie Ann Nastasi

The occupational lives of individuals with visual impairment reveal adaptation to a world clearly processed through vision. Through a collective case study, the researcher collected and analyzed data on the occupational lives of three individuals with visual impairment. Occupational adaptation served as the theory underpinning the study. Instruments to collect data included a demographic questionnaire, visual assessments, the Self-report Assessment of Functional Visual Performance, the MOS Social Support Survey, semi-structured interviews, and observations. The researcher analyzed the data by case study and across the case studies. Three themes emerged from the cross-case analysis: an occupational life of doing, an occupational life rich with well-being, and an occupational life filled with motivation for independence. The participants were highly motivated to complete their occupations and activities independently. Participation in activities in the home and community environments provided participants with life satisfaction and happiness. Problem solving skills, adaptations, and support of family and friends allowed the participants to achieve relative mastery of their occupations.

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## **CHAPTER ONE**

### **INTRODUCTION**

The occupational lives of individuals with visual impairment reveal adaptation to a world clearly processed through vision. An occupational life consists of human experiences in everyday activities, which make up the roles, habits, and routines of an individual. Individuals with visual impairment engage in activities because of specific roles, habits, or routines. Influenced by individuals' socio-cultural backgrounds, roles help form individuals' self-identities. Routines provide individuals with visual impairment with structure for living while habits consist of automatic behaviors (American Occupational Therapy Association (AOTA), 2014). The occupational lives of individuals with visual impairment require adaptations for successful participation in activities and tasks of varying complexity.

When individuals with visual impairment participate in activities, the activities take place in different environments and contexts and have different demands. The environments, contexts, and demands may support or hinder participation in activities. The environments and contexts include cultural, personal, temporal, virtual, physical, and social environments and contexts (AOTA, 2014). The demands for individuals with visual impairment include the relevancy and importance to the individuals, the actual objects being used and

their properties, the space in which the activities are completed, social aspects, timing and sequencing, the required actions and performance skills needed, and body structures and functions necessary to complete the activities.

Individuals with visual impairment have deficits in visual acuity and/or visual fields, which result in non-corrective errors. This means that eyeglasses or contact lenses will not correct their vision. How individuals with visual impairment process and use their available vision greatly varies depending on the area of vision affected. Visual acuity deficits range from low vision (20/70) to total blindness (no light perception). Individuals with low vision often benefit from hand-held and stand magnifiers, closed-circuit televisions, and large print materials. Individuals who meet the criteria of legal blindness range from 20/200 visual acuity to total blindness where there is no light perception (NLP). Strategies and adaptations greatly vary depending on the severity of the blindness for the individual. Individuals with some vision use the remaining vision with the other senses and adaptive techniques. Individuals with no vision compensate through the other senses and adaptive techniques.

Individuals with visual impairment may have deficits in both visual acuity and visual field. Visual field loss occurs in the central and/or peripheral fields. Individuals with central field loss have trouble with reading, writing, detecting facial expression, and seeing detailed information. Individuals with peripheral field loss have trouble navigating in different environments, lose track of objects on surfaces, and have problems detecting moving objects and light. Some individuals have mild impairments that may result in increased time and effort to

complete an activity while others experience extreme impairment where they are unable to process any vision or any light. Whether individuals have a mild impairment (low vision) or profound visual impairment (blindness), the individuals face challenges living in a world created for the sighted.

In order to live in a world created and designed for the sighted, individuals with visual impairment need to adapt to the vision loss. Some individuals are born with visual impairment while others experience vision loss sometime after birth. Vision loss may result from an injury or a disease. Some eye conditions are stable while some other eye conditions progress resulting in further vision loss over time. Depending on the degree of vision loss, the strategies and adaptations to compensate for vision loss vary due to the complexity of the vision loss and the complexity of the activities that individuals want to participate in and complete.

Common adaptations include addressing lighting, decreasing patterns and clutter, increasing contrast, and implementing organizational strategies. For some conditions, increased lighting allows individuals to process visual information while in other conditions glare from lighting is problematic. It is important to make sure lighting facilitates and does not hinder participation in activities. By decreasing patterns and clutter, individuals do not have to process unnecessary information, which increases efficiency and time. The same holds true for increasing contrast. By increasing contrast, individuals' ability to process visual information increases. It is easier to see objects with greater contrast; for example, it is easier to see words written with a black fine tip marker than with a

pencil on white paper. Implementation of organizational strategies also facilitates participation in activities for individuals with visual impairment. By organizing activities into stations and by specific task, it takes less time to locate and use items for a specific task. Organizational strategies developed by individuals help facilitate participation in specific tasks by meeting the individuals' specific needs and requirements. Individuals with no light perception or total blindness do not benefit from increased lighting and contrast, but do benefit from using organizational strategies and decreasing clutter. The complexity of vision loss and activities requires individualization of adaptive techniques.

### **Purpose Statement**

The purpose of this study is to describe the occupational lives of individuals with visual impairment. The study describes the occupations of individuals with visual impairment, community participation, and challenges and adaptations used for their participation.

### **Definitions of Variables**

This study examined the variables of "occupational lives," "visual impairment," and "adaptation." The following paragraphs discuss the definition for each of the variables.

Occupational lives of individuals with visual impairment consist of all the occupations that individuals complete throughout the day from the time of wake until the time of sleep. These occupations include, but are not limited to, activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation (AOTA, 2014). During the

completion of these occupations, individuals with visual impairment encounter challenges, which require occupational adaptation. Individuals with visual impairment will adapt the activity or environment to allow for successful completion of the activity. Activities of daily living (ADL) are activities that are typically oriented toward caring for one's self (bathing, dressing, grooming, eating, feeding, toileting, personal device care, functional mobility, and sexual activity). Individuals with visual impairment typically perform these activities prior to leaving the home, but may also perform the activities outside of the home. Instrumental activities of daily living (I-ADL) require increased cognitive demand compared to ADL. I-ADL (caring for others, caring for pets, child rearing, communication management, driving and community mobility, financial management, health management and maintenance, home establishment and management, meal preparation and clean-up, religious observation and spiritual activities and expression, safety and emergency maintenance, and shopping) typically require individuals with visual impairment to interact with other persons, organizations, or populations (AOTA, 2014). In order to gain the energy needed to participate in all of these activities, individuals with visual impairment must rest and sleep. This consists of resting, preparing to fall asleep, and sleeping. In addition to individuals' participation in ADL, I-ADL, and rest and sleep, individuals with visual impairment also participate in educational activities, work, play, leisure, and social participation. Educational activities provide individuals with visual impairment with the opportunity to learn. Learning may be informal, such as learning a hobby, or formal, such as preparing for a career. Work activities

may or may not be paid activities. Work encompasses the skills needed for individuals with visual impairment to seek and acquire a job, perform the job, plan and adjust to retirement, and explore and participate in volunteer activities. Adults typically do not participate in play, but rather participate in leisure activities. Play, the work of children, provides children with the opportunity to explore and participate in activities. Leisure also provides individuals with visual impairment with the opportunity to explore and participate in activities, and is intrinsically motivating (AOTA, 2014). Leisure time consists of time free of required occupations. Individuals with visual impairment partake in enjoyable activities. Finally, social participation consists of individuals' engagement with family, friends, peers, and community. Individuals' roles change depending on whom they are participating in activities with.

In this study, visual impairment consists of low vision and blindness as defined by the International Statistical Classification of Diseases and Related Health Problems – 10 (ICD-10) classification codes for visual impairment (World Health Organization (WHO), 2012). The ICD-10 defines visual impairment into five categories. The categories correspond to individuals' levels of visual acuity. Categories I and II represent low vision, and categories III, IV, and V represent blindness. In order to minimally qualify as a category I, individuals' best corrected-vision needs to be 20/70 or worse in the better eye. This means with eyeglasses or contact lenses, their better eye needs to be at least 20/70. When individuals' visual acuity is 20/70, individuals with visual impairment see at 20 feet what other individuals with normal sight would see standing 70 feet away

from the object being viewed, thus decreasing the clarity and detail of the viewed object. The maximum qualification is no light perception (NLP). This means these individuals with visual impairment experience total darkness.

Finally, adaptation refers to alternative methods used by individuals with visual impairment or changes made to the environment in order to allow individuals with visual impairment to participate in activities or occupations. Individuals with visual impairment use remaining vision and/or other senses including, but not limited to, functions of hearing, vestibular, taste, smell, proprioceptive, touch, pain, and temperature and pressure in order to participate in activities or occupations (AOTA, 2014). Additionally, individuals with visual impairment may alter habits, routines, rituals, and roles. Alterations to cultural, personal, temporal, virtual, physical, and social contexts and environments allow individuals with visual impairment to participate in activities or occupations (AOTA, 2014).

## **Background**

The theory of occupational adaptation underpins the examination of the occupational lives of individuals with visual impairment. Individuals with visual impairment respond and adapt to occupational challenges (Schkade & McClung, 2001). According to Schkade and Schultz (1992), life roles allow individuals with visual impairment to gain competence in occupational functioning. Over time, individuals with visual impairment will encounter challenges in occupational performance. The greatest challenges will present when individuals with visual impairment experience transitions. Transitions occur when these individuals

experience progressive loss of vision, or when they must function in unfamiliar environments. Individuals with visual impairment will either successfully adapt or remain maladaptive. When individuals with visual impairment have the ability to complete an occupation, press for mastery occurs (Schkade & McClung, 2001).

This means the interaction of individuals with visual impairment and the environment requires changes in order to yield success. For example, individuals with visual impairment may write with a black fine tip marker, which provides contrast in order to be able to read hand-written materials. Individuals with visual impairment achieve relative mastery when able to adapt to the occupational press thus allowing for the completion of the occupation.

Occupational adaptation identifies human and environmental components that affect the ability to complete an occupation. Individuals with visual impairment learn to adapt to the challenges based on previous attempts and knowledge (Schkade & McClung, 2001). Occupational adaptation occurs when individuals with visual impairment are able to successfully adapt and complete the desired activity (Wiley, 2004).

Vision accounts for 90% of the information brought in through the central nervous system. For individuals with visual impairment, this creates challenges in everyday activities and occupations that need vision to provide information quickly. Individuals with vision may quickly scan a room to see where a coat is located. In contrast, individuals with visual impairment need to employ organizational strategies that will allow them to move throughout the room and feel for the coat, thus requiring increased time and effort to complete the task.



Rudman, Huot, Klinger, Leipert, and Spafford (2010) found that individuals with visual impairment experienced an enhanced sense of risk. Despite only moderate levels of visual impairment, physical and social spaces for the participants were shrinking. The participants self-limited their participation in valued occupations due to perceived risk. The participants would continually evaluate the amount of risk necessary to complete tasks. If the risks were too high, the participants would stop or eliminate the tasks.

### **Prevalence of Low Vision**

Visual impairment affects 285 million people worldwide and 3.3 million Americans 40 years of age and older (WHO, 2012; National Eye Institute (NEI), 2004). It is predicted that in the United States of America, the number of people affected by blindness and low vision will be 5.5 million people in the year 2020 (NEI, 2004). Literature on the effects of visual impairment, low vision, and blindness on occupational engagement is limited. In a study by Rudman et al. (2010) of older adults with low vision, themes emerged that the older adults had an enhanced sense of risk, which resulted in shrinking physical and social life spaces. The older adults would weigh out the benefits and risks necessary to complete an occupation. The study used the Visual Function Questionnaire-25 (VFQ-25) and found only moderate levels of self-perceived visual impairment, yet the individuals were stopping valued occupations and limiting their physical and social environments.

### **Significance of Study**

The findings of this study help occupational therapists and occupational scientists to understand the occupational lives of individuals with visual impairment. This study is important to the fields of occupational therapy and occupational science because it provides descriptions of how individuals with visual impairment participate in occupations. These descriptions will help occupational therapists and occupational scientists to understand better the occupational lives of individuals with visual impairment in order to plan better interventions and programs for individuals with visual impairment. Currently there is limited research on the occupational lives of individuals with visual impairment because low vision rehabilitation is an emerging practice area (Brachtesende, 2005). Information provided by this study will assist practitioners in developing tools and assessments for the visually impaired as well as relevant interventions and adaptations. The stories of these individuals expose adaptation and restriction of occupations because of visual impairment. The findings provide research in an area of practice that has limited research.

### **Research Questions**

This study answered the following research questions:

What are the occupational lives of individuals with visual impairment?

- What vision do the participants have?
- What are the activities of daily living (ADL) and instrumental activities of daily living (I-ADL) performance levels of the participants?
- What strategies maximize the participants' participation in occupations?

## Definitions

Occupational life: All of the day to day occupations and their associated interactions and strategies that promote an individual's adaptation, transitions, and overall participation in life.

Occupations: Occupations include, but are not limited to activities of daily living, instrumental activities of daily living, rest and sleep, education, work, play, leisure, and social participation (AOTA, 2014).

Interactions: The relationship and exchange between individuals, the occupation, and the environments in which they occur (Cole & Tufano, 2008)

Strategies: An individual's repertoire of adaptive occupational responses used to successfully complete a desired occupation (Schkade & McClung, 2001).

Adaptation: The use of alternative senses and methods by individuals or changes made to the environment to allow individuals to participate in activities or occupations (Schkade & McClung, 2001).

Transitions: Transitions are changes, passages from one stage to another (Schkade & McClung, 2001); such transitions, or changes, occur when individuals experience progressive loss of vision, engage in new occupation(s), or must function in new or unfamiliar environments or circumstances.

Participation: An individual's engagement in occupation (AOTA, 2014).

Visual impairment: A level of visual acuity that meets the qualifications for the ICD-10 classification codes of visual impairment categories I-V. Categories I and II represent low vision, and categories III, IV, and V represent blindness. In order to minimally qualify as a category I, individuals' best corrected-vision needs to be

20/70 or worse in the better eye. Maximum qualification is no light perception (NLP) (WHO, 2012).

## **CHAPTER TWO**

### **LITERATURE REVIEW**

The fields of occupational therapy and occupational science value evidence-based research and evidence-based practice. The researcher conducted a literature review to determine the level of evidence available on the occupational lives of individuals with visual impairment. The chapter first examines the literature published on the occupation-based theory of Occupational Adaptation (OA). The chapter then explores literature found on the meaning of occupation and its' history. The chapter concludes with a review of literature specific to visual impairment, assessment, and the occupations of individuals with visual impairment. The literature review will provide the conceptual framework, identify weaknesses and gaps in the current literature, and demonstrate the need for further study in the area of the occupational lives of individuals with visual impairment.

#### **Occupational Adaptation (OA)**

Occupational adaptation (OA) emerged as an occupation-based theory in 1992 to the field of occupational therapy. The *American Journal of Occupational Therapy* published two articles introducing the model to the profession (Schkade & Schultz, 1992; Schultz & Schkade, 1992). Faculty at Texas Woman's University developed the theoretical frame of reference to provide a research focus for the occupational therapy education program and a guide for therapeutic

intervention for clinical practice (Schkade & McClung, 2001). Schkade and Schultz's (1992) articles presented the field with a new guideline for contemporary practice. Lee (2010) conducted an evidence-based review covering the years of 1980 through July 31, 2009, and reported publications for the OA model include one textbook, seven book chapters, nineteen refereed publications, and four non-refereed publications. From August 2009 to date, the CINAHL database displays twenty-one additional publications for the model (CINAHL, 2014). The model focuses on the person, the occupational environment, and the interaction between the person and the occupational environment. When the person's abilities and the occupational environment's demands match, the person achieves relative mastery. When the person's abilities do not match the occupational environment's demands, press for mastery occurs. The model presented a normative process to explain the steps the person takes while seeking the ability to adapt to a situation (Schkade & McClung, 2001).

Schkade and Schultz (1992) articulated the assumptions and elements of OA. They expressed that the model's most important assumption is that occupation provides the mechanism for persons to adapt to change and the person's intrinsic desire to participate in occupation leads to adaptation. In this model, challenges occur during periods of transition. Transitions happen during changes in life roles or as the result of illness, accident, or disease. By participating in meaningful occupations, the person learns different strategies and methods to call upon when encountering an activity that creates an occupational

challenge. The person is then able to call upon previous knowledge to adapt to meet the needs of the challenge and successfully complete the activity or task. When this occurs, the person achieves relative mastery, the overall goal of the model. The next sections will discuss the three elements of the model: the person, the occupational environment, and the interaction between the person and the occupational environment; also discussed will be the relevancy of the model today.

### **The Person**

Schkade and McClung (2001) articulated that individuals have their own internal expectations. Genetic, environmental, and phenomenological subsystems shape the sensorimotor, cognitive, and psychosocial systems of individuals. As a result, individuals have their own unique internal role expectations that influence how they respond to an occupational challenge. For example, individuals with visual impairment will employ different strategies than individuals with vision when looking for an object in a room (cognitive). Individuals with vision will scan a room using vision to find an object; in contrast, individuals with visual impairment will employ organizational strategies to search systematically throughout the room. By evaluating individuals based on their sensorimotor, cognitive, and psychosocial systems and then developing specific intervention plans, successful adaptation occurs. When individuals successfully adapt, relative mastery occurs.

## **The Occupational Environment**

Schkade and McClung (2001) reported that the occupational environment provides the context and external expectations for the individuals. Within the element of the occupational environment are the work, play/leisure, and self-care environments. Physical, social, and cultural subsystems contribute to the work, play/leisure, and self-care environments. How individuals complete an activity or task will differ depending on the physical, social, and cultural subsystems. For example, individuals' responses in a classroom with no windows and a single overhead light will differ from the response when bright sun enters the room through windows and the room has ample overhead lighting filling the room with natural day light (physical environment). The social subsystem would trigger individuals to respond differently when eating lunch with friends than when eating lunch alone. Finally, the cultural subsystem would prompt individuals to interact with friends at a club or organization differently than when at a funeral. Schkade and McClung (2001) contend that by evaluating the occupational environment, the occupational therapist facilitates proper intervention for occupational adaptation. Again, when individuals successfully adapt relative mastery occurs.

## **The Interaction between the Person and the Occupational Environment**

Schkade and McClung (2001) presented that individuals' desires for mastery and the occupational environment's demands for mastery create a press for mastery. When individuals' abilities and the occupational environment's demands do not coincide, an occupational challenge presents. At the same time, individuals' role expectations and the occupational environment's role



expectations generate an occupational response. Individuals typically choose one of three responses. One, individuals continue to try to complete the activity or task using the same method. Two, individuals utilize an adaptive response that was successful in the past. Three, individuals create a new adaptive response. Once individuals have employed one of the three responses, they evaluate the adaptive response and the outcome of the response. If individuals are unsuccessful and do not achieve the desired outcome, individuals will look for a different adaptive response. If individuals are successful, individuals achieve relative mastery of the activity or task (Schkade & Schultz, 1992).

### **The Relevancy of Occupational Adaptation Today**

Since the birth of OA, numerous published studies and dissertations have utilized OA as an underpinning theoretical model for their studies. Developed at Texas Woman's University, both faculty and doctoral students (Andersson, 2004; Bradley, 2009; Brayman, 1998; George, 2001; George, Schkade, & Ishee, 2004; McDuff, 2009; Schkade & McClung, 2001; Schkade & Schultz, 1992; Schultz & Schkade, 1992; Schulz, 2002; Wiley, 2004) have published research using the model of OA. The fields of occupational therapy and occupational science have also embraced OA and published research using the model (Buchanan, & Peterson, 2014; Cahill, Connolly, & Stapleton, 2010; Klinger, 2005; Lee, 2010; Lee, Madden, Mason, Rice, Wyburd, & Hobson, 2006; Lexell, Iwarsson, & Lund, 2011; McDougall, Williams & Murray, 2013; McIntyre & Howie, 2002; Moyers & Coleman, 2004; Pepin & Deutcher, 2011; Thompson, 2009; Vrkljan & Polgar, 2007; Whiteford, 2007).

Lee (2010) reviewed and synthesized literature, and found evidence supporting the use of OA for cerebral vascular accidents, hip fractures, elderly with chronic illnesses, and adolescents with limb deficiencies. In addition, Lee found examples of OA application in children and adolescents with mental health problems, persons with carpal tunnel syndrome, homeless persons, older workers, community-dwelling elders, forensic psychiatry, home-health, and level II fieldwork students. The application of OA crossed many areas of practice in the fields of occupational therapy and occupational science. These studies, however, did not mention that individuals sustaining cerebral vascular accident, elderly individuals with chronic illnesses, homeless persons, older workers, and community-dwelling elders may experience visual impairment. Cerebral vascular accidents, traumatic brain injury, or tumors may affect the visual cortex resulting in hemianopsia (Mogk, 2011), and after the age of forty, natural changes occur in the eyes resulting in central or peripheral field loss or both (Kaldenberg & Smallfield, 2013).

Literature after Lee's (2010) review included evidence of using the OA model with persons with low vision (Rudman, Huot, Klinger, Leipert, & Spafford, 2010), stroke (Williams & Murray, 2013), and multiple sclerosis (Cahill, Connolly, & Stapleton, 2010; Lexell, Iwarsson, & Lund, 2011), as well as persons in retirement (Pepin & Deutcher, 2011). The use of OA continued to benefit both researchers and clinicians who selected OA as the theoretical frame of reference to guide their research and clinical intervention.

Rudman et al. (2010) used the OA model as a theoretical framework for their study of older adults who were 70 years of age or older with low vision that did not seek rehabilitation. They found that the participants in the study had an enhanced sense of risk and shrunk their physical and social spaces. “The essence of the experience of living with low vision was that of a constant struggle to maintain engagement in valued and necessary occupations while dealing with risk perceived as resulting from one’s low vision” (p.90). The participants would weigh the benefits of occupations, which had previously been part of their routines, with the risks associated with engaging in the activities. Participants stopped participating in occupations that previously provided pleasure and social contact because of the physical and social risks associated with participation in the occupations. However, the participants reported completing activities of daily living and other activities deemed necessary to perform in the home despite risk. The elimination of community activities reduced perceived risks for the participants.

The Rudman et al. (2010) study determined that individuals with visual impairment who do not seek rehabilitation limited their participation in meaningful community activities. This raises the question: Is rehabilitation the solution? In order to know if rehabilitation is the solution, we need to know more about the occupational lives of individuals with visual impairment who participate in the community. By studying individuals with visual impairment who participate in the community, occupational therapy practitioners and occupational scientists will learn how these individuals have adapted to their visual impairment and achieved

relative mastery. Using the OA model as a theoretical framework, this study will identify the occupational lives of individuals with visual impairment.

### **Meaning of Occupation**

Reitz (2010) reported the fields of occupational therapy and occupational science value the role of occupation in the promotion of health and wellness. “Occupations are central to a client’s (person’s, group’s, or population’s) identity and sense of competence and have particular meaning and value to that client” (AOTA, 2014, p. S5). Occupations are complex and have multiple dimensions to them while activities typically refer to specific tasks. Occupations may require persons, groups, or populations to complete many activities within the occupation. The definitions of occupation vary, but in general, the definitions encompass the concepts of completing an activity or activities that are purposeful and meaningful to achieve a goal. “The term occupation denotes life engagements that are constructed of multiple activities” (AOTA, 2014, p. S6). In practice, occupational therapy practitioners and occupational scientists often use the terms occupation and activity interchangeably.

### **History of Occupational Therapy and Occupational Science**

Wilcock (2001) reported the profession of occupational therapy emerged from the Moral Treatment that occurred during the late eighteenth and early nineteenth centuries. The Moral Treatment embraced a humane approach for addressing the needs of individuals with mental illness. Kielhofner (2009) included addressing the physical, temporal, and societal aspects of the environment to facilitate individuals’ participation in occupations. Since its

conception, the field of occupational therapy has undergone paradigm shifts and changes; however, concepts from the Moral Treatment have remained, allowing the field of occupational therapy to expand and address clients (persons, groups, and populations) in a variety of contexts and environments (AOTA, 2014).

In 1917, George Barton, William Dunton, Eleanor Clark Slagle, Susan Cox Johnson, Thomas Kidner, and Isabel Newton met in Clifton Springs, New York and created a certificate of incorporation for the National Society for the Promotion of Occupational Therapy. This created the first official association for the field of occupational therapy. The National Society for the Promotion of Occupational Therapy remained the official name of the association until 1921, when the membership voted and changed the name to the American Occupational Therapy Association (AOTA; O'Brien & Hussey, 2012).

Since its birth, the field of occupational therapy has evolved to meet societal needs. O'Brien and Hussey (2012) reported that during the 1920s occupational therapy focused on habit training and the reconstruction of the soldiers returning from war. Occupational therapists worked with the soldiers under the supervision of physicians to assist the soldiers in returning to work. Crafts and recreation were commonly used as therapeutic interventions (Kielhofner, 2009).

During the 1930s, the field shifted into biomechanical and behavioral frames of reference as the field of medicine searched for scientific and modern treatments (O'Brien & Hussey, 2012). However, in the 1940s World War II brought occupational therapy back to vocational rehabilitation as the soldiers

returned from war. World War II introduced soldiers with complex injuries who survived their injuries in war due to advances in medicine. The biomechanical and rehabilitation models emerged during this time. The biomechanical model provided guidance for treatment of physical injuries while the rehabilitation model provided guidance for compensation and the use of adaptive equipment to complete activities (Kielhofner, 2009; O'Brien & Hussey, 2012). During the 1950s the psychoanalytic and sensory motor models emerged (O'Brien & Hussey, 2012). Occupational therapy began to focus on the use of self as a therapeutic tool.

The 1950s also marked the beginning of the Eleanor Clarke Slagle Lecture awarded by the AOTA. The award was named after Eleanor Clarke Slagle, in recognition of all of her contributions to the profession. The AOTA has not awarded the Eleanor Clarke Slagle honor every year. No one received the award in 1964, 1968, 1970, 1977, 1982, 1991, 1992, 1997, and 2002 (Padilla & Griffiths, 2011). The themes and topics presented in the Eleanor Clarke Slagle Lectures demonstrate the paradigm shifts and changes that have emerged over time as the field of occupational therapy shifted to meet societal needs. Padilla and Griffiths (2011) reported that the Slagle lectures in the 1960s focused on theories while the lectures in the 1970s focused on growth and expansion of the profession. During the 1980s the lectures addressed the profession's identity while the lectures in the 1990s revisited occupation.

The Eleanor Clarke Slagle Lectures from the 1990s brought the profession's focus back to occupation and introduced occupational science to the

field of occupational therapy. The decade began focusing on human resilience (Fine, 2011), using occupations to heal (Clark, 2011), and making the community the place for engaging in occupations (Grady, 2011). As the decade progressed, the profession called for the need for research (Nelson, 2011; Trombly, 2011) and a practice framework (Fisher, 2011). Florence Clark's lecture introduced the field of occupational science and its' use of storytelling (Clark, 2011). Charles Christiansen reintroduced the concept of storytelling in his lecture that discussed life stories (Christiansen, 2011), and David Nelson called for occupational therapy research by occupational therapists and those who know occupational therapy.

Padilla and Griffiths (2011) identified the 1990s as a turning point in the professions of occupational therapy and occupational science. Occupational therapy returned to its roots in occupation; while the field of occupational science, which emerged during the late 1980s and early 1990s out of the Department of Occupational Therapy at the University of Southern California in Los Angeles, gained its place as a profession. Clark et al. (1991) reported the field of occupational science would provide the field of occupational therapy with doctoral level faculty, scientific research, and justification and enhancement of occupational therapy practice. Born in the United States of America, the profession expanded internationally. In 1993, the *Journal of Occupational Science: Australia* published its first volume. The journal officially changed its name in 1998 to the *Journal of Occupational Science* (Taylor & Francis Group, 2014). In 1999, the International Society for Occupational Science held its

inaugural meeting in Australia (International Society of Occupational Science, 2009).

In November 2002, a group of scholars in Galveston, Texas met and formed the United States of America's first official society for occupational science called the Society for the Study of Occupation: USA (SSO: USA), 2002).

Padilla and Griffiths (2011) reported occupational therapy and occupational science in the new millennium have continued to focus on evidence-based practice (Coster, 2011; Holm, 2011) and occupation (Dunn, 2011; Hasselkus, 2011; Hinojosa, 2011; Peloquin, 2011; Royeen, 2011; Schwartz, 2011; Zemke, 2011). The Centennial Vision for the AOTA stated, "We envision that occupational therapy is a powerful, widely recognized, science-driven, and evidence-based profession with a globally connected and diverse workforce meeting society's occupational needs" (AOTA, 2014, par. 1). The fields of occupational therapy and occupational science both recognized the need for science-driven research, evidence-based practice, and the need to remain globally connected.

### **The Focus of Occupational Therapy and Occupational Science on Occupation**

Wilcock (2001) reported while the fields of occupational therapy and occupational science are relatively new professions, the concepts of occupation, and using occupation for health and wellness, date back prior to the naming of the professions. Human occupations have existed since the beginning of time.



The Bible contained some of the early stories of human occupation.

Wilcock's (2001) *Occupation for Health, Volume 1* identified "the fall of humankind" in Genesis where "people were condemned to work for their survival and health" after eating the forbidden fruit (p. 30) and Deuteronomy's "accounts of people cultivating and harvesting grain, olives and grapes" (Wilcock, 2001, p. 33). The stories focused on the contributions provided to society through the participation in occupation.

Reitz (2010) shared stories of the early philosophers, Pythagorus and Thales, using music as a therapeutic modality, and the Chinese using activities in 2600 BC for prevention and treatment. Occupations have played a vital role in the health and participation of persons, groups, and populations (AOTA, 2014) both prior to the naming of the professions and since the official incorporation of the professions.

The fields of occupational therapy and occupational science have created professions dedicated to promoting independence and participation in occupations and activities. AOTA (2014) reported occupations and activities can range from very simple to very complex in nature. It is the role of occupational therapists to promote "health, well-being, and participation in life" (AOTA, 2014, p. S11). Occupational therapists accomplish this through the client-therapist collaborative process of evaluation, intervention, and outcomes. During the evaluation, occupational therapists create an occupational profile where therapists gain an understanding of the client's occupational history and experiences. The client identifies the problems and concerns that are affecting

his/her ability to complete occupations and activities. Occupational therapists then analyze the client's occupational performance.

Occupational performance refers to “the accomplishment of the selected occupation resulting from the dynamic transition among the client, the context and environment, and the activity or occupation” (AOTA, 2014, p. S14).

Occupational therapists and occupational therapy assistants then work with the client to improve the client's engagement in occupations or activities (AOTA, 2014). Occupational therapists and occupational therapy assistants consider client factors such as values, beliefs, spirituality, body functions, and body structures that play a role in the client's occupational performance, as well as the environment or context where the activity takes place, and the demands of the activity.

Whiteford and Townsend (2011) reported that while the field of occupational therapy focuses on evaluation and therapeutic interventions to maximize client participation and engagement, the field of occupational science focuses on researching the role and meaning of occupational engagement, and empowering occupational justice.

### **Occupational Lives**

Occupational lives consist of human experiences in everyday activities, which make up the roles, habits, and routines of individuals. The occupational lives of individuals should be inherently different. Hocking and Whiteford (2012) identified through the lens of occupational science that occupation has the power to address global inequities. It is important to understand the availability of

occupations to individuals. Depending on individuals' situations, individuals may experience occupational injustice.

Munoz et al. (2011) reported occupational injustice occurs when alienation, apartheid, deprivation, imbalance, or restriction occur. Occupational alienation occurs when individuals sense powerlessness and experience estrangement from society. This results in an inability to gain enjoyment from occupations. Occupational apartheid refers to segregation and denial of access to occupations based on race, disability, gender, religion, sexual preference, or other characteristics of the person (Munoz et al., 2011). Based on one of their characteristics, individuals may not participate in a desired activity. Occupational deprivation occurs when an external agency stops individuals from acquiring, using, and enjoying activities or occupations (Wilcock, 2006) while occupational imbalance refers to the uneven distribution of labor and the benefits resulting from labor (Arnold & Rybski, 2010). Finally, occupational restriction refers to individuals having no choices or options for engaging in occupation except for those controlled by their superiors (Munoz et al., 2011).

Literature denotes that participation in occupations promotes health and wellness for individuals (Eakman, 2014; Eakman & Eklund, 2012; Hakansson, Dahlin-Ivanoff, & Sonn, 2006; Hammell, 2014; Hammell & Iwama, 2012; Reid, 2008; Stav, Hallenen, Lane, & Arbesman, 2012; Stevens-Ratchford, 2014; Wensly & Slade, 2012). The act of doing (Bendixen et al., 2006; Eriksson et al., 2011; Erlandsson, 2013; Law, 2010; Persson, Andersson, & Eklund, 2011; Reid, 2011; Smith, Ludwig, Andersen, & Copolillo, 2009; Wilcock, 1999) allows

individuals to achieve a greater motivation for independence (Rudman et al., 2010; Tay, Drury, & Mackey, 2014). The study of the occupational lives of individuals with visual impairment will provide information on occupational justice and occupational injustice. By identifying areas of occupational injustice, occupational scientists and occupational therapy practitioners may work together to provide opportunities for occupational engagement and participation.

### **Occupations in the Lives of Individuals with Visual Impairment**

In order to live and engage in a world created and designed for the sighted, individuals with visual impairment need to learn to adapt to vision loss. Globally, individuals with visual impairment and blindness represent 285 million people. Of the 285 million people, 246 million have low vision and 39 million are blind. Eighty-two percent of those who are blind are 50 years of age or older (WHO, 2012). In the United States of America, the Centers for Disease Control and Prevention (CDC) reported that 1.6 million Americans age 50 or older have age-related macular degeneration, while 2.2 million Americans age 40 or older have glaucoma and 20.5 million have cataracts (CDC, 2009). As the baby boomers enter older adulthood, the number of older adults with low vision is expected to double by 2020, and there will be 88.5 million Americans over 65 years of age in the year 2050 (Sternberg, 2013). As the number of older adults increases, the number of people experiencing visual impairment from low vision and blindness will also increase. Individuals with visual impairment struggle to maintain independence in visually dependent occupations and activities, which previously presented no challenges or risks. Rudman et al. (2010) reported that

without proper rehabilitation, individuals' occupational engagement and participation in activities in the community are restricted.

Visual impairments range on a scale from low vision to total blindness based on individuals' visual acuity and visual fields. The next sections of this chapter will focus on low vision and blindness, the areas of vision affected by low vision and blindness, and the current research available on the occupational lives of individuals with visual impairment.

### **Low Vision and Blindness as it Relates to Participation**

Since the creation of the International Classification of Function (ICF), the WHO also created the *ICF Checklist* (WHO, 2003) to assist in eliciting information about the function and disability of individuals. The checklist defines activity as the execution of a task and participation as the involvement in a life situation. Activity limitations occur when individuals have difficulty executing activities, and participation restrictions occur when individuals face problems in life situations (WHO, 2003). The areas of activity and participation include learning and applying knowledge, general tasks and demands, communication, mobility, self-care, domestic life, interpersonal interactions and relationships, major life areas, and community, social and civic life, as well as any other activity and participation. Environmental factors include products and technology, natural environment and human changes to environment, support and relationships, attitudes, and services, systems and policies, as well as any other environmental factors.

The WHO recommended using the *ICF Checklist* along with the ICF when evaluating individuals' ability to participate in activities (WHO, 2013). The overall goal of the WHO is to promote health in disadvantaged and vulnerable groups of people (WHO, 2007). Vision specific goals for the WHO include eliminating avoidable blindness, expanding access to eye health services, and increasing rehabilitation for individuals with visual impairment and blindness (WHO, 2013).

**Visual acuity.** Visual acuity measures individuals' ability to see an object at a specific distance. The eye doctor typically measures distance visual acuity using a Snellen chart. The large "E" at the top of the Snellen chart represents 20/200 vision (Mogk & Goodrich, 2004). Individuals with 20/200 visual acuity see at 20 feet the same quality that individuals with normal vision see standing 200 feet away from the same object. The Snellen chart uses a logarithmic measurement scale. The examiner needs to ensure the proper test distance for individuals or the results will be invalid. Individuals receive credit for the smallest line read with at least fifty percent accuracy. The American Medical Association defines individuals with a visual acuity of 20/200 or less as legally blind (Mogk & Goodrich, 2004). The Snellen chart only detects vision to 20/200. Individuals with visual impairment require charts with greater sensitivity to determine their level of visual impairment.

Intermediate visual acuity charts provide greater sensitivity for testing distance vision of individuals with visual impairment. The examiner ensures that the individuals tested maintain the proper distance in order to validate the results of the test. Most intermediate visual acuity charts include Snellen conversions on

the charts. The WHO defines the levels of visual impairment using the Snellen fractions. The Low Vision Lea-numbers Chart for intermediate visual acuity assesses visual acuity to 20/1000 when administered at one meter (Warren, 2005). Physicians prescribe appropriate optical devices and make referrals based on the level of visual impairment.

The examiner will also test the near visual acuity for individuals with visual impairment. Near vision charts determine the level of visual acuity when looking at objects within arm's reach. Near visual acuity measurements assist the examiner in determining proper interventions for reading tasks. Physicians assess near visual acuity to determine if individuals need eyeglasses, magnifiers, or electronic magnification to complete near tasks.

**Visual fields.** Individuals' visual fields consist of the central visual field and the peripheral visual field. The macula, the central 20 degrees of the visual field, processes the central field of vision (Kaldenberg & Smallfield, 2013). The central field of vision consists of rods and cones, which allow individuals to process colors and see detailed information. Kaldenberg and Smallfield (2013) reported that damage to the central field of vision leads to impairments in reading, writing, detecting details, driving, and recognizing colors. The peripheral visual field consists of rods that detect movement and light. When the peripheral field detects movement, individuals will turn their heads to see what the peripheral field detected. Kaldenberg and Smallfield (2013) reported that damage to the peripheral field of vision may result in tunnel vision, hemianopsias, or quadrantanopsias.

A physician will assess the central and peripheral visual fields to determine whether a field loss is present. Meyers and Wilcox (2011) reported that tangent screens and bowl perimeters assessments assist the physician in determining the location of a field loss. Field losses may occur in the central visual field, the peripheral visual field, or in both fields. The information yielded from the assessments assists physicians in prescribing optical devices, such as prisms, to compensate for field loss (Nowakowski, 2011) or in determining the need for rehabilitation to address strategies of compensation.

**Contrast sensitivity.** Mogk (2011) reported that contrast sensitivity refers to the ability to distinguish objects that are similar in color. Deficits in contrast sensitivity may result in difficulty seeing water on the floor, cut outs on curbs, facial features, and liquids. Physicians assess contrast sensitivity using contrast sensitivity function tests. Meyers and Wilcox (2011) reported that the tests measure the percentage of contrast individuals detect. The examiner will administer the test at different distances. Warren (2005) reported that at the closest distance, individuals detect the greatest range of contrast. The range decreases at further distances.

### **Current Research on the Lives of Individuals with Visual Impairment**

Living in a world created for the sighted presents many challenges to individuals with visual impairment. Rudman et al. (2010) conveyed that in order to maintain functional independence and engage in purposeful and meaningful occupations, individuals with visual impairment need to access and receive rehabilitation services to overcome the barriers and risks associated with vision



loss. In order to understand the experiences of individuals with visual impairment, the researcher completed a literature review on the occupational lives of individuals with visual impairment.

To date, literature published does not delve into the occupational lives of individuals with visual impairment. Literature exists on the specific occupations and programs made available to individuals with visual impairment, but in-depth research on individuals' experiences and their occupational lives does not exist. This final section of the chapter will discuss the areas of occupation, the literature found on the areas of occupation as they relate to individuals with visual impairment, rehabilitation, and recommendations and considerations for occupational therapy practitioners and occupational scientists when working with individuals with visual impairment.

**Defining Occupation in Relation to Daily Life.** The AOTA (2014) classified occupations into the categories of activities of daily living (ADL), instrumental activities of daily living (IADL), rest and sleep, education, work, play, leisure, and social participation. Individuals with visual impairment participate in these areas of occupation on a daily basis. ADL are activities that are typically oriented toward caring for one's self. Individuals with visual impairment typically perform the activities prior to leaving their home, but the activities are not restricted to the home environment. ADL include bathing, showering, toileting, dressing, eating, feeding, functional mobility, personal device care, grooming, and sexual activity (AOTA, 2014).

IADL are more complex than ADL. Individuals with visual impairment typically complete these activities in the home or community environments. By nature, the activities require complex interactions and may involve other persons or organizations. IADL include care of others, care of pets, childrearing, communication management, community mobility, financial management, health management and maintenance, home establishment and management, meal preparation and cleanup, religious observation, safety and emergency maintenance, and shopping (AOTA, 2014).

Other areas of occupation include rest and sleep, education, work, leisure, and social participation. Rest and sleep refer to all of the activities that are involved in preparing to fall asleep. Rest and sleep include rest, sleep, sleep preparation, and sleep participation (AOTA, 2014). Education refers to activities that individuals need to complete in order to learn and participate. This includes formal education participation, informal personal education needs or interest exploration, and informal personal education participation (AOTA, 2014). Work refers to employment and volunteer activities. This includes employment interests and pursuits, employment seeking and acquisition, job performance, retirement preparation and adjustment, volunteer exploration and volunteer participation (AOTA, 2014). Play refers to activities that are planned or unplanned that provide enjoyment or entertainment (AOTA, 2014). Play falls into the categories of play exploration and play participation. The activity of play is typically associated with children, while adults participate in leisure activity.

Leisure activity is any intrinsically motivating and engaging activity that an individual completes in free time. Leisure, like play, falls into the categories of leisure exploration and leisure participation (AOTA, 2014). Finally, social participation consists of behaviors that society expects of individuals as members of society. Social participation takes place at the peer/friend, family, and community levels. Behaviors and expectations vary depending with whom individuals are interacting (AOTA, 2014). Literature found for each of these areas follows in the immediate sections.

***Activities of daily living as part of life for the visually impaired.***

Eklund, Sjostrand, and Dahlin-Ivanoff (2008) completed a randomized controlled trial of a health-promotion program for individuals with age-related macular degeneration. They randomly assigned participants into a health-promotion group or an individual intervention group. Eklund et al. (2008) evaluated each participant's ability to bathe, dress, toilet, transfer, and feed him or herself. They also evaluated the IADL of the participants. Based on the findings, the researchers provided training on ADL and IADL during the health-promotion sessions. Two occupational therapists ran the health-promotion sessions for two hours, once a week, over a period of 8 weeks. Participants in the individual intervention group received one- to two-hour long sessions and a follow-up telephone call within 2-4 weeks of the session(s). The individual intervention group also received optician prescribed glasses and occupational therapy prescribed low-vision aids. Eklund et al. (2008) found the health-promotion group maintained their ADL level despite significant decreases in visual acuity,

while the individual intervention group became more dependent in their ADL.

They attributed the problem solving skills developed during the health-promotion sessions as the reason for success despite further visual impairment.

***Instrumental activities of daily living as part of life for the visually impaired.*** Studies on IADL for individuals with visual impairment included studies on health-promotion (Eklund, Sjostrand, & Dahlin-Ivanoff, 2008), care giving (Fuhr, Martinez, & Williams, 2008), community mobility (Bedsen, 2009; Carrico, 2010; Emerson & Sauerburger, 2008; Erin, 2009; Havik, Steyvers, van der Velde, Phillips, 2011; Matsunaka & Koda, 2008; Picard & Pry, 2009; Pinkster, & Kooijman, 2010), communication management (Wong & Tan, 2012), daily living (Lamoureux et al., 2008), lighting (Evans, Sawyer, Jessa, Brodrick, & Slater, 2010), and adaptive equipment (Fok, Polgar, Shaw, & Jutai, 2011). Detailed information for the studies follows.

*Health-promotion program to facilitate engagement in life.* As mentioned previously, the Eklund et al. (2008) health-promotion program also evaluated the ability of individuals with age-related macular degeneration to clean, shop, travel, and cook. The health-promotion group maintained their level of independence while the individual intervention group became more dependent as their visual impairment worsened. Eklund et al. (2008) attributed the success of the health-promotion group to the problem solving abilities developed during the health-promotion sessions. Problem solving skills enable individuals with visual impairment to work through challenges and achieve relative mastery (Schkade & McClung, 2001).

*Facilitating care giving after visual impairment.* Individuals with visual impairment may need to serve as caregivers to other family members. Fuhr, Martinez, and Williams (2008) studied individuals with visual impairment who served as caregivers. They gathered the case reports of three participants in a pilot one-week intensive low vision program at the Birmingham Department of Veterans Affairs. All three participants were legally blind and the caregivers of their wives. For 5 days, each received 3 hours of visual skills training, 2 hours of independent living skills, 1 hour of medication management, and 2 hours of rehabilitation that included orientation and mobility skills. Participants learned how to use illuminated pocket and stand magnifiers for reading and closed-circuit televisions for reading, writing, and identifying medication. Participants also learned techniques for cooking and medication management, as well as how to use lighting, contrast, and organization to maximize their independence. Upon completion of the weeklong program all reported great satisfaction, and wished that they could stay for more training. All three were independent in medication management and one said, "In just one week, I have a new life" (Fuhr, Martinez, & Williams, 2008, p. 92). The multidisciplinary approach to providing training allowed the caregivers to gain the skills needed to care for their spouses and themselves.

*Community mobility techniques for individuals with visual impairment.* In order to travel independently in the community, individuals with visual impairment need to receive training in community mobility. Havik et al. (2010) designed and evaluated a two-phase protocol for assessing the usefulness of the Trekker 3.0

as an electronic travel device for orientation and mobility. They recruited twenty participants and nineteen participants completed the study. The first phase of the study was the identification phase, where they tested the participant to determine if an electronic aid was appropriate. During the second phase, the intervention phase, the participant received structured training on the device. Participants received the typical training session from the distributor and then received three additional two-hour individual training sessions. During the individual training sessions, six organized modules of increased complexity were covered. Seven participants completed the training in the three additional sessions. The remaining participants needed a full session per module. All of the variables measured in the study improved from the first training with the distributor to the last session of the protocol. Havik et al. (2010) completed the study over a six week interval and recommended that six weeks be given to habituate the individual to the device in order to demonstrate and experience the device for his/her particular situation.

In addition to the results of the study described, two studies supported the use of tactile maps (Bedsen, 2009; Erin, 2009) and one the use of tactile exposure to small scale models of the environment (Picard & Pry, 2009). Phillips (2011) supported training students in the use of GPS for travel while Emerson and Sauerburger (2008) reported that alternative routes of travel that use traffic controls are necessary for the safety of blind travelers. The technique of waiting until it is quiet to cross a street without traffic controls is not a safe practice. Their study tested different conditions and in at least one of the conditions, the

participants were not safe to cross the road. Community mobility and risks associated with community mobility create barriers for individuals with visual impairment.

*Visual impairment and communication management.* Advances in technology have presented opportunities and barriers for individuals with visual impairment. Wong and Tan (2012) reported technologies like the iPhone provided individuals with visual impairment with applications for identifying colors, digit-eyes, and money readers. A software engineer worked with a man who used the JAWS screen reader for his computer and optical character recognition scanning software. The software engineer trained the man to use the applications (apps) on his cell phone that ultimately reduced the number of devices the man needed to carry with him. The transition to using the apps on the phone presented some challenges. The challenges included the inconsistency of some apps when used with VoiceOver, difficulty locating apps, and the need for “hand-holding” when learning the potential apps (Wong & Tan, 2012, p. 649).

*Daily living of the visually impaired.* Typical daily living activities affect the ability of individuals with visual impairment to participate in everyday activities. Lamoureux et al. (2008) assessed the Impact of Vision Impairment (IVI) as an instrument to measure participation in daily living activities and rehabilitation for individuals with age-related macular degeneration. The study found that reading ordinary size print, reading labels or instructions on medication, and shopping caused the individuals with age-related macular degeneration the greatest

difficulty. Challenges to these areas create barriers for participation.

Occupational scientists and occupational therapy practitioners need to be aware of these challenges when working with individuals with visual impairment.

*The importance of lighting for individuals with visual impairment.* Lighting plays an important role in individuals' ability to participate in occupations. Evans et al. (2010) studied the impact of lighting on individuals with cataracts, age-related macular degeneration, and cataracts with age-related macular degeneration. They found significant findings for the participants in the study. For individuals with cataracts, using the brightest lighting significantly affected the individuals' reading rates and ability to walk corridors. In medium lighting, these individuals had significant findings for sorting pills. Evans et al. (2010) also found significant findings for individuals with age-related macular degeneration. In the brightest lighting, the individuals were able to plug a cord into a socket. Finally, for individuals with cataracts and age-related macular degeneration, the rate of reading was significant under medium lighting. Evans et al. (2010) recommended addressing lighting on an individual basis.

*The use of adaptive equipment by the visually impaired.* Adaptive equipment provides individuals with visual impairment with the means of completing different tasks. Fok et al. (2011) interviewed adults 18 years of age or older with visual impairment that used at least one piece of adaptive equipment. Participants needed to have low vision as their primary diagnosis, use sight-enhancing devices like magnifiers or electronic screen magnification, and be able to participate in a telephone interview. Fok et al. (2011) found



participants reported low use of white canes. Only 47% of participants with moderate to severe low vision used a cane. In addition, participants ranked assistive technology devices and occupations. Participants reported using a combination of devices. One of the participants reported not realizing the number of technology devices they used until stating them aloud. Participants rated glasses and sunglasses among the most important devices, and reported using optical devices as well as computer systems. When incorporated correctly, adaptive devices became a normal part of life.

***Rest and sleep as part of life for the visually impaired.*** No research presented for the area of rest and sleep. Casual observation in the clinic indicates that individuals with low vision and blindness use adaptive alarm clocks and other equipment to ensure proper rest and sleep. Research on the effectiveness of adaptive equipment and strategies is recommended for this area.

***Education as part of life for the visually impaired.*** Education is one of the major occupations of children and young adults. Lyons, Johnson, and Majzoub (2011) reported on the importance of vision centers in schools to evaluate and address the visual deficits of children. Haddad et al. (2009) found that optical correction and low vision aids were efficient in improving educational inclusion for children with congenital glaucoma. Providing optical correction facilitated participation in the educational setting.

Kelly and Smith (2011) examined literature from 1965 to 2009 on assistive technology's impact on the performance of students with visual

impairments. They found that virtually no studies have used rigorous scientific methods to determine the effectiveness of the assistive technology for students with visual impairment. There were numerous articles published on assistive technology for classroom-based intervention (ages 3 to 21); however, the studies did not use scientific methods to assess the effectiveness of the technologies. Much of the literature focused on anecdotal evidence and theory. Kelly and Smith (2011) recommended that studies follow higher standards.

Other research found in the area of education included braille reading (Britcher, 2009; Serino, 2009), e-learning (Evans & Douglas, 2008; Fichten, Asuncion, Barile, Ferrari, & Wolforth, 2009; Sapp, 2009), videophone technology (Emerson & Bishop, 2012), and student engagement (Bardin & Lewis, 2008). Detailed information from the studies follows.

*Training students in Braille reading.* When teaching braille reading to students, Britcher (2009) reported success when incorporating motivating activities for the students. She used multisensory activities to motivate students. Examples included beach balls with braille messages on the different sections of the ball, including stickers and scented items within books, and recording electronic messages in books. Britcher also used modified playing cards with braille to allow children to participate in the game of War in math class. Serino (2009) also motivated students to read by allowing the students to select the materials that they were going to read.

*E-learning for the visually impaired.* Sapp (2009) discussed the importance of universal design for online educational media. This included two

tiers of captioning and audio description. For captioning, there was a need for standard captioning and concise captioning. Standard captioning provided actual narration while concise captioning simplified vocabulary and grammatical structure. For audio description, there was a need for standard format and expanded description format. Standard audio description provided a detailed description of visual components. Expanded description provided information prior to playing a video, which enhanced the context and meaning for the learner. Evans and Douglas (2008) reported that it takes students that are blind twice as long to complete e-learning tasks as students without visual impairment. Students with low vision performed better than students who were blind when completing e-learning materials (Fichten et al., 2009).

*Videophone technology for the visually impaired.* The National Center for Technology Innovation funded the “Seeing the Possibilities with Videophone Technology” project for children with deaf-blindness from birth to 21 years of age. Emerson and Bishop (2012) recruited participants for the project who were 14 to 21 years of age and participated in an educational setting. Sorenson Communications provided 22-inch television monitors for each videophone unit. Participants received a unit for their home and their school. Ten students participated in the study. Emerson and Bishop (2012) collected the participants’ data through videophone logs maintained by the participants’ families, the lead investigator’s check-in calls, and through the Intrinsic Motivation Inventory (IMI). They found increased accessibility for interpersonal communication among students with deaf-blindness. Students communicated more when at home than

at school. The units provided increased opportunity for social interactions. The students' experiences broadened, allowing for motivation and joy as well as independence.

*Classroom engagement of students with visual impairment.* Bardin and Lewis (2008) studied the engagement of students with visual impairment in the classroom. They surveyed the students' teachers. The educators identified students with visual impairment as moderately engaged. Bardin and Lewis (2008) showed that half of the students with visual impairment were performing at grade level, 21% were working above grade level, and 26% were performing below grade level. Educators perceived braille reading students performing above grade level compared to print readers, but the statistics showed that there was no significant difference between the two groups. Bardin and Lewis (2008) recommended that teachers of students with visual impairment should measure the students' levels of engagement and develop appropriate interventions to increase the engagement of the students in areas that are weaker.

***Work as part of life for the visually impaired.*** "For individuals with visual impairment and blindness there are many barriers to employment" and only 40-45% of these individuals in the United States are employed (Kaldenberg, 2011, p. 1). Three case studies (Markowitz, Markowitz, & Markowitz, 2011; Robertson, 2011; Crow, 2008) and a study of employment factors (Clement, Douglas, & Pavey, 2011) reported on work issues for individuals with low vision and blindness. In addition, the review found two studies on social support in the

workplace (Papakonstantinou & Papadopoulos, 2010; Papakonstantinou & Papadopoulos, 2009).

*Case studies of individuals with visual impairment.* Markowitz, Markowitz, and Markowitz (2011) reported on a case study of a 47-year-old worker with low vision. An ophthalmologist prescribed optical devices and an occupational therapist enhanced the worker's reading and writing skills. In addition, the occupational therapist performed a workplace assessment to optimize the worker's functional vision. The occupational therapist provided the worker with interventions over 4 weeks. The interventions included changing the lighting in the work environment, recommending less travel between external facilities, training the worker in audio recording devices and adjustable reading stands, and sessions to improve writing. At the end of the training, the worker was able to write 1M size print continuously. The interventions increased the worker's independence in work tasks.

Robertson (2011) reported on a human rights complaint of a worker who alleged her employer would not allow for reasonable accommodations for her vision deficits. An occupational therapist completed a functional work evaluation of the worker. It included a functional capacity evaluation, clinic-based driving assessment, behind-the-wheel driving assessment, and work place assessment. The occupational therapist found that the worker was able to complete the physical, visual and driving demands of the occupation with minimal accommodations. The worker's biggest restriction was her limitation of driving during the night. The occupational therapist recommended sales trips during day

light hours and planning an overnight hotel stay for sales trips in the winter, which was not usual for sales trips. The British Columbia Human Rights Tribunal received the occupational therapist's evaluation and found the worker's employer did not properly accommodate the worker's disability.

Crow (2008) wrote a practice report on a student who became the California School for the Blind's student cane-repair person. The student learned how to repair canes on National White Cane Day. When the student learned that the school was not going to have a cane-repair activity for the next National White Cane Day, the student worked with Crow on cane repair, organizing her workspace, and skills for communicating with customers. The student created a one-day-a-week, 90-minute job for herself. The job provided the student with increased self-esteem and greater problem solving skills. While the student required some assistance with certain aspects of the job, the student was able to work independently most of the time.

*Employment factors for the visually impaired.* Clements et al. (2011) analyzed the factors that affect the ability of British people who are registered as blind or visually impaired to work. Educational attainment, housing tenure, registration status, and having additional disabilities all had the strongest impact on working. Clements et al. (2011) identified that men ages 30-49, with a degree qualification or higher, who had their own home with dependent child(ren), who were registered as visually impaired without any additional disability, and whose visual impairment started between birth and 16 years of age were most likely to be employed. They reported that education was one of the most powerful

interventions available to individuals with visual impairment in order to enter the workforce.

*Social support for the visually impaired.* Papakonstantinou and Papadopoulos (2010) completed a follow-up study to their 2009 study of social support in the workplace. The initial study found more cases of positive social support than negative social support for the participants. In 2010, the researchers had 25 participants with visual impairments complete a questionnaire with 15 open- and closed-ended questions and in-depth interviews to identify types of social support. Data was categorized as positive practical support, negative practical support, positive emotional support, and negative emotional support. They reported that this was the first study to explore the positive and negative forms of support. Their study provided a tool for resolving problems with relationships at work.

*Play as part of life for the visually impaired.* Current literature on play is limited. A study on audio platform games for players with visual impairment (Oren, Harding, & Bonebright, 2008) and a practice report on teaching jump rope (Lieberman, Schedlin, & Pierce, 2009) were found. Oren et al. (2008) found that a simple video game translated into a challenging audio game for individuals with visual impairment. They made the source code for their game publically available so individuals with visual impairment could edit it and create new levels to play and share with friends. Lieberman et al. (2009) reported on strategies for jumping rope for children with visual impairments. They identified a systematic progression that children could perform sequentially or as individual activities.

The authors reported that jumping rope improved physical activity as well as socialization skills.

***Leisure and social participation as part of life for the visually impaired.*** Current literature on leisure participation and social participation is limited. A systematic review on interventions to improve leisure and social participation for individuals with low vision (Berger, McAteer, Schreier, & Kalenberg, 2013), a study on participation in the elderly (Alma et al., 2011), and a study on facial emotion (Boucart et al., 2008) were found. Berger et al. (2013) reviewed 13 articles that met the criteria for their systematic review. The themes of using a problem solving approach, receiving a combination of services, skills training, and receiving home visits and environmental adaptations were found to improve leisure and social participation. Alma et al. (2011) found that elderly with visual impairment participated less in heavy household activities, recreation activities and sports. Eighty-eight percent of their participants (n=173) reported restrictions in leisure activities. Participants also reported restrictions in household activities (84%), socialization (53%), and paid or voluntary work (92%).

Boucart et al. (2008) studied the ability of individuals with age-related macular degeneration to recognize facial emotion. Facial emotion provided important information during social participation. They found that participants used the low spatial frequencies for expression because they were unable to perceive finer detail. The participants preferred looking at the mouth to determine expression. Boucart et al. (2008) found that color improved facial and



object recognition in photographs for individuals with low vision. Color and crowd reduction helped individuals with the spatial properties of the image.

Research on leisure and social participation is limited and there is a need for further research in the areas for individuals with visual impairment. Leisure and social participation are indicators for successful aging and attribute to positive influence on health and well-being (Alma et al., 2011).

### **Rehabilitation for the Visually Impaired**

For individuals with visual impairment, everyday activities in the home and in the community present challenges. Rudman et al. (2010) studied older adults who were 70 years of age or older with low vision that did not seek rehabilitation. They found that the participants in the study had an enhanced sense of risk and shrunk their physical and social spaces. The participants would weigh the benefits of occupations, which had previously been part of their routines, with the risks associated with engaging in the activities. Participants stopped participating in occupations that previously provided pleasure and social contact because of the physical and social risks associated with participation in the occupations. However, the participants reported completing activities of daily living and other activities deemed necessary to perform in the home despite risk. The elimination of community activities reduced risks for the participants.

One risk, fear of falling, contributed to limiting physical spaces and social contact (Rudman et al., 2010). In a study by Boyce, Stone, Johnson, and Simkiss (2013), visual impairment contributed to 47 percent of falls. Older adults with macular degeneration were 2.4 times more likely to fall and 2.8 times more

likely to experience an injury from falling (Sternberg, 2013). However, when fall reduction plans addressed visual impairment, older adults with visual impairment decreased their risk of falling as much as 14 percent (Boyce et al., 2013).

For older adults with glaucoma, limitations in peripheral vision resulted in problems such as difficulty navigating in the community because of visual limitations in search, and lack of ability to identify objects and hazards in the community. For older adults with diabetic retinopathy, problems occurred in navigating in dynamic environments. Difficulties in navigation resulted from decreased ability to detect, identify, and locate people and changes in terrain. Participation in rehabilitation allowed individuals with visual impairment to learn strategies to modify the context, environment, activity demands and client factors to reduce restrictions and increase participation in valued occupations (Sternberg, 2013).

Studies by Southall and Wittich (2012) and Crudden and Sansing (2011) used focus groups to identify additional barriers to low vision rehabilitation services and service delivery to individuals with visual impairment. Southall and Wittich (2012) found that individuals with visual impairment were not always aware of low vision rehabilitation services available and many faced societal barriers creating limitations in transportation options. Crudden and Sansing's study (2011) found themes of variability in services, outreach, service delivery, and transportation. Participants reported an increased need for consumer awareness and outreach on services and adaptive equipment available to individuals with visual impairment. Participants also reported that services made

available varied, and that more services were available in urban areas than in rural areas. Finally, participants reported that transportation created a barrier for accessing rehabilitation services because of the lack of availability and unreliable services. Rural areas had limited access to transportation while urban areas faced unreliable and unmanageable public transportation systems (Crudden & Sansing, 2011).

### **Family Support for the Visually Impaired**

A systematic review conducted by Bambara, Wadley, Owsley, Martin, Porter, and Dreer (2009) found that the majority of literature on family functioning and low vision focused on the unique role that family played in providing instrumental and emotional support to the visually impaired. Family members provided instrumental support by assisting the individual with visual impairment in everyday living tasks, and they provided emotional support by encouraging the individual during difficult times. The reviewers found individuals with visual impairment relied more heavily on family support than support from friends.

Individuals with visual impairment receiving instrumental support from family adapted better to vision loss and had greater life satisfaction, and fewer symptoms of depression. However, when family members lacked knowledge about the individual's visual impairment, the family members tended to overprotect the individual. Individuals with visual impairment receiving emotional support from family reported good communication with family members and well-established networks of social support. The positive attitudes of family members played an important role. When family members understood the individual's

vision loss the individual gained independence. This affected the overall well-being of the individual (Bambara et al., 2009).

Bambara et al.'s (2009) review identified limited research on the effect of the vision loss on the family's psychosocial adjustment. They identified a need for future research on the effect on family as well as the need to discuss the implications of the effect on family in clinical practice.

### **Literature Review Summary and Need for Future Research**

As stated at the beginning of the chapter, the fields of occupational therapy and occupational science value evidence-based research and evidence-based practice. The researcher reviewed and examined literature on the theory of occupational adaptation, the meaning of occupation and its history, literature specific to visual impairment, assessment, and the occupations of individuals with visual impairment.

Occupational adaptation (OA), as it relates to individuals with visual impairment, provides guidelines to further understand individuals with visual impairment, the environment, and the interaction of individuals with visual impairment and the environment (Schkade & Schultz, 1992). During transitions, individuals with visual impairment face challenges in their occupations. When faced with challenges, individuals with visual impairment are required to select an occupational response (Schkade & McClung, 2001). The occupational response may be to try the same method used in the past, using a different adaptation that was successful in the past, or trying a new adaptive response (Schkade & McClung, 2001). Individuals' motivation to remain independent enables them to

complete desired occupations. When individuals with visual impairment are successful in their occupations, they achieve relative mastery.

Individuals with visual impairment are occupational beings, and find meaning in participating in occupations (Schkade & Schultz, 1992). The OA model provides researchers and clinicians with the opportunity to look at individuals with visual impairment, the environment, and the interaction of individuals with visual impairment and the environment during participation in occupations. The findings of Lee (2010) and Rudman et al. (2010) indicate the use of OA with individuals with visual impairment. OA was found applicable across a wide variety of practice areas (Lee, 2010), and was used to guide the Rudman et al. (2010) study of older adults with visual impairment that did not seek rehabilitation. When individuals with visual impairment did not seek rehabilitation, they shrank their physical and social spaces to avoid risk. However, these same individuals continued to complete occupations deemed necessary to complete in their homes despite the risk.

Occupation has been linked to health and wellness (Reitz, 2010) since the beginning of humankind (Wilcock, 2001). The history of occupational therapy begins in 1917 (O'Brien & Hussey, 2012), and has evolved to meet societal needs over time (Padilla & Griffiths, 2011). Occupational science emerged during the late 1980s and early 1990s to provide scientific research on humans' participation in occupations (Clark et al., 1991).

Globally there are 285 million people with visual impairment (WHO, 2012). The World Health Organization has established vision-specific goals to address

expanding access to eye health services and increasing rehabilitation for individuals with visual impairment (WHO,2013). Tools like the *ICF Checklist* (WHO, 2003) assist occupational therapists and occupational scientists in eliciting information on the function and disability of individuals with visual impairment.

Rehabilitation has provided individuals with visual impairment with the opportunity to learn strategies and techniques to remain independent. Individuals with age-related macular degeneration that participated in a health-promotion program maintained their ADL and IADL level despite declines in their visual acuity (Eklund et al., 2008). Caregivers with visual impairment reported greater life satisfaction and independence after receiving a week of intensive rehabilitation (Fuhr et al., 2008). Individuals with visual impairment who received training to use an electronic travel device for community mobility gained independence in mobility after receiving six weeks of training (Havik et al. 2010). Individuals with visual impairment who were trained in technology reduced the number of devices they needed to carry to remain independent in activities (Wong & Tan, 2012). Individuals with visual impairment who received rehabilitation gained problem solving skills for leisure and social participation (Berger et al., 2013). In the work place, individuals with visual impairment that received on-site rehabilitation gained independence in work functions (Markowitz et al., 2011; Crow, 2008). For play, individuals with visual impairment learned strategies to jump rope (Lieberman et al., 2009), and source coding enabled individuals with visual impairment to play audio games (Oren et al., 2008).

In addition to rehabilitation, education provided in the school setting has allowed individuals with visual impairment to succeed. Clements et al. (2011) found that education provided opportunities for individuals with visual impairment to gain employment. Clements et al.'s (2011) findings indicate that individuals with visual impairment that have completed post-secondary education were more likely to obtain employment. Strategies used for students with visual impairment in schools vary. Haddad et al. (2009) found that students who received vision aids were more efficient in inclusion settings. Britcher (2009) and Serino (2009) found the use of motivating techniques facilitated students' participation in Braille reading. The use of captioning and audio description enhanced e-learning for students with visual impairment (Sapp, 2009). However, on-line learning required students with visual impairment to spend twice as much time to complete a task that students without visual impairment completed (Frichten et al., 2009).

Finally, individuals with visual impairment that received instrumental and emotional support from family adapted better to vision loss and had greater life satisfaction, fewer symptoms of depression, and greater communication and networks of social support (Bambara et al., 2000).

Individuals with visual impairment participate in everyday activities. To date, no literature exists on the occupational lives of individuals with visual impairment. The occupational lives of individuals with visual impairment consist of the human experiences in everyday activities that make up the roles, habits, and routines of the individuals.

Based on the literature reviewed, there is a need to reveal a broader picture of the lives of individuals with visual impairment. By revealing the occupational lives of individuals with visual impairment, occupational scientists and occupational therapists will be able to facilitate intervention techniques and create environments to support and enable occupational performance. Ultimately, this will allow individuals with visual impairments to be able to participate and be included in everyday occupations (Letts, Rigby, & Stewart, 2003). This ultimately will allow for the health and wellness of these individuals through participation in occupations (Reitz, 2010).



## **CHAPTER THREE**

### **METHODS AND MATERIALS**

This study explored the occupational lives of individuals with visual impairment. Values and principles from the professions of occupational therapy and occupational science provided the framework used to define the occupational lives of individuals with visual impairment. This chapter addresses the rationale, assumptions, theoretical lens, research design, research sample, data collection methods, data management, and data analysis of the study.

#### **Rationale**

A collective case study, a series of case studies, captured the occupational lives of individuals with visual impairment through the lens of occupational science. By exploring the occupational engagement of individuals with visual impairment, occupational therapists and occupational scientists will gain a better understanding of the occupational lives of individuals with visual impairment, thus allowing for the development of tools and assessments for the visually impaired as well as relevant interventions and adaptations to maximize participation for individuals with visual impairment.

#### **Assumptions**

The researcher believes that all individuals have the capacity to adapt to challenges in their occupations and environments. Through adaptation, individuals achieve the ability to participate in meaningful activities and

occupations. Through participation in these activities and occupations, individuals build a greater repertoire of experiences to draw upon when occupations and/or environments require adaptation for successful participation. Individuals may develop adaptation strategies from their own experiences or from skills learned from rehabilitation professionals, family, and friends.

### **Theoretical Lenses**

The present study used occupational science and occupational adaptation to serve as the theoretical lenses for this study. The researcher used the occupations of individuals with visual impairment to explore and understand community participation and participation within the home. The researcher explored challenges and adaptations used by the participants for their participation in both contexts. This study used the participants' engagement in occupations to generate knowledge of the occupational lives of individuals with visual impairment.

### **Research Design**

This qualitative research study used a collective case study to gain a better understanding of the occupational lives of individuals with visual impairment. The collective case study should help to reveal the unique lives of individuals with visual impairment, and the shared themes among the individuals. The experimental method is a powerful one but it is not always feasible; and the case study methodology helps provide rich detail. The collective case study allowed for the exploration of the stories and experiences of individuals with visual impairment.

The researcher used the collective case study as a methodology to explore the lives of individuals with visual impairment who attend the Lackawanna Blind Association. The collective case study methodology incorporated the use of multiple sources for data including visual assessments, profiles, surveys, observations, and interviews. By using multiple case studies, data were analyzed for each case study individually as well as across cases, allowing for a better understanding of the phenomenon (Hitchcock & Newman, 2012).

Several researchers have reported the use of collective case studies. The collective case study methodology has been used to examine transitions (Smith, Drefus, & Hersch, 2011), learning disabilities (Kolanko, 2003), education (Jones, 2009), learning (Ilari, 2013), mentoring (Orland-Barak & Hasin, 2010), and writing (Olthouse, 2013). Strengths of the collective case study methodology include a more comprehensive understanding of a phenomenon (Orland-Barak & Hasin, 2010), the relationships between individuals and occupations (Ilari, 2013), and the ability to gather personal outcomes (Smith, Drefus, & Hersch, 2011). The collective case study methodology allows for greater depth of understanding of context and process, and understanding and linking of causes and outcomes (Flyvbjerg, 2011). Weaknesses of the collective case study methodology include a weakened understanding of occurrence (Smith, Drefus, & Hersch, 2011) and the inability to test for statistical significance in the study (Flyvbjerg, 2011). Overall, the collective case study methodology provides a meaningful

understanding of real-life, and provides knowledge that cannot otherwise be generalized (Flyvbjerg, 2011).

**Boundaries of the study.** For this study, a collective case study captured the occupational lives of three individuals with visual impairment that attend the Lackawanna Blind Association in Scranton, Pennsylvania. All participants were adults 65 years of age or older who have experienced visual impairment for over five years. Participants lived within Lackawanna County, Pennsylvania and participated in at least one program at the Lackawanna Blind Association. The study addressed the individuals' participation at the center, their participation in the community, the environments in which they participate, and their adaptation to vision loss. The study explored the occupational lives of the individuals individually (case analysis) as well as across the individual cases (cross-case analysis).

### **Research Sample**

Recruitment of participants took place at the Lackawanna Blind Association. The Lackawanna Blind Association served as the partnering site for the study. The agency is a 501 (c) (3) non-profit corporation registered with the Pennsylvania Bureau of Charitable Organizations and is accredited by the National Accreditation Council for agencies serving people with blindness or visual impairments. Its' mission is to support and promote the interests of the blind and visually impaired, as well as the prevention of avoidable blindness throughout Lackawanna County, where there are an estimated 6,000 individuals with visual impairment. Individuals with visual impairment register with the

Lackawanna Blind Association to receive services provided through the agency. Services include Pell radio reading service, prevention of blindness services, social activity programs, social services, client support services, a vision resource center, and visual support center. All clients must meet the visual impairment classifications of the World Health Organization (WHO, 2013), with a minimal qualification of best-corrected visual acuity of 20/70 in the better eye to a maximum qualification of total blindness or no light perception.

**Sampling procedures.** This study sampled individuals who participated at the Lackawanna Blind Association. Recruiting participants from a community-based agency for the visually impaired allowed access to a population of individuals with visual impairment that participate in activities outside of the home. The researcher gathered an in-depth understanding of the occupational lives of three individuals, who had visual impairment and who attended at least one program at the Lackawanna Blind Association. Programs offered at the Lackawanna Blind Association include sensory development classes, life skills and exercise classes, the Shopland Club, and a support group. By selecting participants from this specific community-based agency, it eliminated the possibility of gathering information from individuals who do not have visual impairment as well as individuals who do not leave their home and participate in the community. In addition, it limited the participants to a specific geographic area. At the time of the study, the Lackawanna Blind Association only serviced individuals with visual impairment living in Lackawanna County in Pennsylvania, United States of America. The agency now also provides services to

Susquehanna County, on the northern border of Lackawanna County.

Occupational lives include activities of daily living (ADL), instrumental activities of daily living (IADL), rest and sleep, education, work, play, leisure, and social participation (AOTA, 2014). Therefore, the study recruited individuals with visual impairment that already participate in the community in order to gain a better understanding of their occupational lives.

**Selection criteria.** Recruitment of participants was coordinated through the Lackawanna Blind Association. Employees of the agency notified their clients of the research study. Clients needed to meet the following eligibility criteria in order to participate in this study:

1. Be registered to receive services at the Lackawanna Blind Association.
2. Meet the World Health Organization's qualifications for visual impairment (minimum of best-corrected visual acuity of 20/70 in the better eye, to a maximum of total blindness or no light perception).
3. Participate in at least one program at the Lackawanna Blind Association.
4. Have a visual impairment for over 5 years.
5. Be at least 65 years of age.

Exclusion criteria included non-English speaking, no visual impairment, having a visual impairment less than 5 years, not participating in a program at the Lackawanna Blind Association, and age less than 65 years.

Interested clients notified employees at the Lackawanna Blind Association of their interest in participating in the study. Employees of the Lackawanna Blind Association then notified the researcher of the clients' interest and scheduled a

time for the clients to meet the researcher. Clients met the researcher individually, and were provided additional information about the study.

The researcher did not anticipate that a large number of clients would be interested in participating in the study based on the boundaries of the study. Three participants from a previously completed pilot study indicated interest in participating in the study. All three participants had similar visual acuity during the pilot study (20/400 or 20/500 visual acuity). The researcher utilized information from the demographic questions on The Occupational Lives of Individuals with Visual Impairment Demographic Questionnaire (OLIVIDQ; see Appendix C) and accepted the three participants for the study, who met the criteria.

**Participants.** One male and two female volunteers participated in this study. Participants were Caucasian; their ages ranged from 65 to 87 years of age with an average age of 79 years. All participants lived in Lackawanna County, Pennsylvania and attended the Lackawanna Blind Association for weekly programs and lunch. At the time of selection, the participants' visual acuity ranged from 20/200 to 20/1000 with correction. The participants had lived with visual impairment for eight years or more and owned and have used closed-circuit televisions for reading activities. All participants were retired and living independently in the community. They were independent in activities of daily living, and on a weekly basis participated in leisure activities outside of the home. The participants relied on family and friends, and various private and public forms of transportation for travel. All participants had familial support on a daily basis.

The participants' scores on the MOS Social Support Survey ranged from 74-91 indicating that participants had a strong level of support. The familial support contributed to the participants' independence in instrumental activities of daily living. Participants' education ranged from some high school to a college degree. Participants described their overall health and quality of life as fair to good, and rated their emotional well-being between eight and nine on a scale of one to ten.

### **Data Collection Methods**

Prior to collecting data, the study received approval from the Office of University Research Services at Towson University and the Departmental Review Board (DRB) at the University of Scranton. A letter of support was obtained from the Lackawanna Blind Association and provided to the Office of University Research Services at Towson University and the DRB at the University of Scranton. An institutional review board (IRB) application was completed, submitted, and approved by both universities (see Appendix A). Upon approval, the Lackawanna Blind Association received a copy of the approved IRB applications for the agency's files.

**Data collection procedures.** The following steps outline the procedure used to gather data for the study:

***Informed consent.*** Each participant was oriented to the study's purpose and procedures. Each participant then provided informed consent to participate in the study. The letter of informed consent provided the participant with the following information: title of the study, contact information for the researcher and the sponsoring institution (Towson University), study description, risks and



benefits, data storage, confidentiality, results, and participant's rights. The researcher read the letter of informed consent to the participants who were unable to read the letter due to their visual impairment. The participants all signed the letter of informed consent.

*Ethical considerations.* Measures were taken to avoid ethical issues throughout the study. The researcher upheld the American Occupational Therapy Association's *Code of Ethics and Ethics Standards* (AOTA, 2010), and maintained ethical behavior that did not put the participants at risk throughout the study. Benefits of the study outweighed any risks associated with the study. Participants encountered no risks during the study and did not need medical or legal intervention. Participants consented to participate in the interview, observation sessions, and follow-up interviews. Participants could have withdrawn from the initial interview, observation sessions, or follow-up interviews at any time, but did not. The measures taken throughout the study ensured privacy for all participants in the study. Participants' responses were accurately recorded, and participants had the opportunity to verify the outcomes of the study.

*Confidentiality.* The researcher maintained the following procedures to ensure confidentiality for the participants. First, each participant completed the demographic questions, visual assessments, SRAFP (see Appendix B), MOS Social Support Survey, and interviews in a private area free from disruption. Second, participants were not identified during the observation session at the Lackawanna Blind Association. Third, follow-up interviews took place in a private

area free from disruption. Finally, all data collected was reviewed and all identifying information was removed, and replaced with an assigned pseudo name. All data was stored in a locked cabinet within a locked office. Upon completion of the study and publication of the findings, the researcher will destroy all data within five years.

*Issues of trustworthiness.* In order to validate the findings of the study and to assure the trustworthiness of the study, the researcher confirmed the codes/themes of the study with the participants during the final interview, and presented the results of the study to each of the participants in the study.

**Test site.** For each interview, participants were met separately in a private office space at the Lackawanna Blind Association. Each interview was audio recorded and transcribed later. The test site had multiple private office spaces and rooms available to interview the participants. All rooms had multiple chairs, desk surfaces, overhead lighting, no natural lighting, and a door to provide privacy. The researcher conducted all of the interviews except for the final interview in the same private office. The final interview was conducted in a different private office due to room availability. All participants completed the final interview in the same private office. For the observation sessions, the researcher attended the programs that the participants participated in at the Lackawanna Blind Association and observed each of the participants for a full twelve-hour day. The researcher served in an observatory role for the observation sessions.

**Data collection and instrumentation.** The researcher collected qualitative and quantitative data over the six sessions of the study.

***First session.*** The initial interview took place during the first session, with data collected via audio recording and note taking. Participants completed the demographic questions from The Occupational Lives of Individuals with Visual Impairment Demographic Questionnaire (OLIVIDQ). See Appendix C for a copy of the OLIVIDQ. After completing the OLIVIDQ, quantitative data for the participants were collected using visual assessments for visual acuity and contrast sensitivity, the Self-Report Assessment of Functional Visual Performance (SRAFVP), and the MOS Social Support Survey.

***Visual instruments.*** The researcher collected data for each participant's visual function. Data were collected for intermediate visual acuity and contrast sensitivity function using the Low Vision Leanumbers Chart with notations at 1 meter Intermediate Acuity Test Chart and the Mars Contrast Sensitivity Test. Both eyes were tested together during data collection.

***The Self-Report Assessment of Functional Visual Performance (SRAFVP).*** After completing the visual assessments, participants completed the SRAFVP. The SRAFVP was administered to each participant to collect data on the participant's ability to complete activities of daily living and instrumental activities of daily living. The participant rated his or her ability to complete a task on a 3-point scale. A score of 1 equaled dependence on others to do the task. A score of 2 represented the ability to complete at least a portion of the task though with difficulty even under optimal conditions. A score of 3 equated to

independence where the participant experienced no difficulty performing the task. If a participant did not perform a task on the profile, the task was not rated. The researcher recorded each of the participants' scores on the scoring form.

*MOS Social Support Survey.* The first session concluded with the completion of the MOS Social Support Survey. The MOS Social Support Survey addresses dimensions of social support for individuals with chronic conditions. The MOS Social Support Survey addresses emotional/informational support, tangible support, affectionate support, and positive social interaction (Sherbourne & Stewart, 1991). The researcher read the instructions of the survey to the participant and asked the participant to identify the level of support available to the participant using the following scale: none of the time, a little of the time, some of the time, most of the time, and all of the time. Each item was read to the participant and then the participant identified the level of support for the item. The researcher recorded the participant's responses.

***Second Session.*** During the second session, participants completed a semi-structured interview with questions from The Nastasi Occupational Lives of Individuals with Visual Impairment Profile (NOLIVIP; see Appendix D) to gather qualitative data. The session was audio-recorded.

*Semi-structured interview.* Participants answered semi-structured questions from the NOLIVIP. The researcher conducted the interview and collected data via audio recording and note taking during the session. At the end of the session, the audio recording was stopped. Recordings were transcribed verbatim for the data collected from the NOLIVIP for each participant.

**Third session.** For the third session, the researcher observed the participants during a program that the participants participated in at the Lackawanna Blind Association. Programs at the agency include, but are not limited to sensory development classes, life skills and exercise classes, the Shopland Club, and a support group. The sensory development classes focus on developing the clients' senses through craft and cooking activities. Life skills and exercise classes provide formal and informal education on nutrition and health as well as structured exercise. The Shopland club provides clients with the opportunity to facilitate their own club and social activities, and the support group provides clients with formal and informal education on living with visual impairment. Field notes were maintained for the observation session.

*Observation.* During the third session, the researcher observed each participant in the life skills and exercise class or Shopland Club meeting at the Lackawanna Blind Association. Field notes were recorded on the participant's engagement, interactions with others, and interactions with the environment. The field notes were typed and analyzed later.

**Fourth session.** Following the observation session, the researcher met with each of the participants for a follow-up interview, which was audio-recorded. The fourth session was conducted after all three participants completed the first three sessions to ensure that the researcher's follow-up questions were applicable across all participants.

*Follow-up interview for first three sessions.* For the fourth session, each participant completed a follow-up interview addressing the first three sessions

(see Appendix E). The researcher sought clarification for data collected during the initial two interviews and observation session. The session was audio-recorded and transcribed later.

***Fifth session.*** For the fifth session, the researcher spent a full day (12 hours) observing the participant's daily activities and maintained field notes for the observation.

*Full-day observation.* For the fifth session, the researcher arrived at the participant's home at the time identified by the participant and followed the participant for the next twelve hours. Field notes were taken as the participant completed his or her typical activities and routines for the day. All of the participants were observed in their homes and in the community during the observation. Field notes for the session included the participant's activities, interactions, and strategies used throughout the day. All field notes were typed and analyzed later.

***Sixth session.*** For the final session, the researcher met with each of the participants for a follow-up interview (see Appendix F). The sessions were audio-recorded and transcribed later. The sixth session was conducted after all three participants completed the first five sessions. The researcher used the final interviews to confirm the codes/themes emerging from the interviews and observation sessions.

*Final follow-up interview.* For the sixth session, the researcher met with each participant to complete a final follow-up interview confirming the codes/themes that emerged from the initial data analysis. Participants were

asked about the identified codes/themes. Additionally, participants had the opportunity to provide additional information and address any areas that they felt had not been addressed. Each final follow-up interview sought confirmation of the initial codes of data analysis. Each session was audio-recorded and transcribed later. In addition, measurements were taken for the intermediate visual acuity of all of the participants during the final interview with the Low Vision Leanumbers Chart with notations at 1 meter Intermediate Acuity Test Chart.

The researcher measured the visual acuities of the participants at the end of the study to determine if the participants had any changes in their vision. This was done to determine whether the participants' visual acuity remained stable throughout the current study.

***Psychometrics of instruments.*** Psychometric data was available for the SRAFP and the MOS Social Support Survey. Occupational therapists at the Eye Foundation of University of Missouri-Kansas City and Washington University developed the SRAFP (Velozo, Warren, Hicks, & Berger, 2013; Warren, Bachelder, Velozo, & Hicks, 2008). In a study of the SRAFP, researchers administered the SRAFP to 102 patients (Velozo et al., 2013). The researchers found good item-level psychometrics for the SRAFP. The SRAFP addressed reading, writing, money management, telephone usage, reading a timepiece, personal care, clothing care, meal preparation, leisure, and functional mobility. By reducing the original five-point rating scale to a three-point scale, researchers were able to correct disordered thresholds, which were occurring in the five-point scale. The SRAFP had good content validity for the vision-dependent activities

of daily living items on the assessment (Warren et al., 2008). The Warren et al. (2008) study established an overall Cronbach's Alpha of .87 for the assessment, with functional reading at .86, food preparation at .84, functional mobility at .87, and functional writing at .84. The inter-rater reliability for the instrument was .97.

The SRAFP used an ordinal scale to collect data. The researchers established Rasch analysis to transfer ordinal data scores into a scale of equal intervals. The instrument created a hierarchy for the 38 items on the assessment that range from easy to complex activities. Rasch analysis confirmed construct validity for the instrument and good person separation reliability (Veloza et al., 2013; Warren et al., 2008).

Research on the MOS Social Support Survey conducted by Sherbourne and Stewart (1991) established reliability and validity for the MOS Social Support Survey. All items on the survey had Alphas > .91 for reliability, and selected construct validity hypotheses were supported (Sherbourne & Stewart, 1991).

### **Data Management**

The researcher managed all data collected during the study, and filed the signed consent forms separately from the data collected during the study to ensure confidentiality for the participants. The following steps were taken to ensure that data for each of the cases remained confidential and accurate. First, assigned pseudo names were written on all documents including but not limited to the OLIVIDQ, SRAFP, MOS Social Support Survey, NOLIVIP, and field notes to distinguish the participants from each other. Participants were assigned the pseudo names of Ann, Jane, and Joe. Second, the beginning of each audio



recording was identified with the date and pseudo name for the participant.

During transcription, all identifying information was removed and replaced with the assigned pseudo name. Finally, the researcher filed all materials and audio recordings for each participant separately and checked all written and audio-recordings to ensure that the materials represented the correct participant.

### **Data Analysis**

This study posed the following research questions:

What are the occupational lives of individuals with visual impairment?

- What vision do the participants have?
- What are the activities of daily living (ADL) and instrumental activities of daily living (I-ADL) performance levels of the participants?
- What strategies maximize the participants' participation in occupations?

The purpose of this study was to explore the occupational lives of three individuals with visual impairment from the Lackawanna Blind Association. Each participant in the study defined a case of the study. The researcher analyzed each case study individually and completed a cross-case analysis for emerging patterns or themes. Data were analyzed for emerging patterns and themes, answering the research questions. Data saturation was reached when patterns were established within and between case studies, and the participants reported no additional information to share. The researcher developed naturalistic generalizations from the analyzed data.

**Areas analyzed.** In order to determine the occupational lives of the participants, information was utilized from the interviews and observation sessions to answer the research questions on each individual's occupational life.

***Participants' vision.*** For the first research question on the participants' vision, data were analyzed from the OLIVIDQ, visual assessments, NOLIVIP, field notes from the observation sessions, and follow-up interviews. The researcher confirmed the qualitative findings of the study with the findings from the visual assessments and the observation sessions.

***Performance levels for ADL and IADL.*** For the second research question on the ADL and IADL performance levels data were analyzed from the participants' responses to the items on the SRAFVP, field notes from the full day observation and the MOS Social Support Survey. Scores from the SRAFVP identified the participants' levels of independence, difficulty, and dependence during participation in activities of daily living and instrumental activities of daily living. Answers from the MOS Social Support Survey identified the level of support available to the participants for their activities of daily living and instrumental activities of daily living.

***Strategies to maximize participation in occupations.*** For the third research question on the strategies to maximize participation in occupations, the researcher analyzed the data collected from the OLIVIDQ, field notes from the observations, visual assessments, MOS Social Support Survey, NOLIVIP, and follow-up interviews. Qualitative findings of the study were confirmed with the findings from the observation sessions.

***Occupational lives of individuals with visual impairment.*** Finally, the researcher analyzed all of the data collected from the OLIVIDQ, visual assessments, SRAFP, MOS Social Support Survey, NOLIVIP, field notes from the observation sessions, and follow-up interviews to answer the overall research question for the study on the occupational lives of individuals with visual impairment. The researcher incorporated concepts from grounded theory to organize the data and establish emerging patterns or themes.

**Grounded theory.** The researcher used grounded theory, as described by Strauss and Corbin (1998), to develop themes by systematically gathering and analyzing data through the research process. The process included data collection, analysis, and theory which were closely interrelated. In this study, the theory of occupational adaptation underpinned the analysis. The researcher open-coded, axial-coded, and selective-coded the data collected for the study.

**Open-coding.** Initially the researcher reviewed data line-by-line and chunked the data (Strauss & Corbin, 1998; Bernard & Ryan, 2010). This process is referred to as open-coding. A matrix was developed for all of the interviews. Data was open-coded on the matrix of interviews. The matrix of interviews included data from sessions one, two, four, and six with the participants. The table format allowed the researcher to organize the data by participant and item. The researcher coded the data by color into the categories of gratitude (purple), loss of participation (red), support (blue), strategies (orange), motivation/independence (green), and participation (brown). The first column on the table addressed the item used to collect data. The second through fourth

columns contained participant's data, the fifth column contained field notes and memos from the researcher, and the sixth column contained the research question that the item addressed. The matrix of interviews contained 228 pages of open-coded data.

***Axial-coding.*** After the text was defragmented, concepts were pulled together. This process is called axial-coding. A matrix for each of the codes was developed. Data was axial-coded on the matrix of codes. The matrix of codes consisted of six tables with five columns. The first column contained the code/theme that the participants verified during the sixth session. The second through fourth columns contained participants' data, and the fifth column contained the overall themes across cases. The researcher gathered all of the data for each code and presented the data in the columns. The first row of each table contained the titles for each of the columns. The second row contained all of the axial-coded data for the participants. The third row contained the participants' responses to the codes/themes presented during the sixth session, and the fourth row contained field notes and memos by the researcher for each of the participants. During axial-coding, the researcher was able to reduce the data from the 228 pages of open-codes to 101 pages of axial-codes.

***Selective-coding.*** Finally, the coding was refined and integrated. This process is called selective-coding. Three tables of selective-codes were created. The tables consisted of four columns. The first column presented the overall code/theme of the study and the second through fourth columns presented the participant's data. During selective-coding, the researcher reduced the data from

101 pages of axial-codes to 45 pages of selective-codes. Overall themes of the study were developed throughout the coding process by merging data from the codes to create the three themes of the study. Data from the codes of strategies, gratitude, and participation yielded the theme of an occupational life of doing. Data from the codes of motivation/independence yielded the theme of an occupational life filled with motivation for independence, and data from the code of support yielded the theme of an occupational life rich with well-being. The themes of an occupational life of doing, an occupational life filled with motivation for independence, and an occupational life rich with well-being emerged during selective-coding.

**Comparison of data.** During data analysis, the researcher compared codes among interview(s). Memos or field notes were created during the coding and served as the first draft of the completed analysis. Themes were refined and built throughout the process. Themes were linked to the participants' rated responses from the SRAFP, MOS Social Support Survey, and observations. Each interview was compared to each other and previous interviews. The researcher integrated the qualitative data with the quantitative data to substantiate the findings of the study.

*Sessions one, two, four, and six.* Qualitative and quantitative data collected during sessions one, two, four, and six were analyzed. The researcher analyzed the qualitative data using the principles of grounded theory as outlined earlier in the chapter. For the quantitative data, the individual findings were analyzed, and cross-case analysis was completed.

*Sessions three and five.* For the observation sessions, the researcher took field notes on each participant's activities, interactions, and strategies used during his or her participation in a program at the Lackawanna Blind Association and during the full day observation. The field notes were analyzed to validate self-reported data collected during the study.

### **Reliability and Validity of Qualitative Data**

The researcher established the validity for the overall findings by having the participants in the study review the codes/themes of the study during the sixth session. All three participants concurred with the codes/themes of the study. The use of member checking ensured accurate depiction of the participants' responses. In addition, the executive director of the Lackawanna Blind Association, caseworker, and caseworker aide who are in regular contact with the clients reviewed the findings. Finally, rich, thick description allows readers to make their own decisions regarding generalizability. An audit trail was maintained throughout the data collection and data analysis to ensure the consistency of procedures for data collection and data analysis.

The researcher established reliability for the study by audio recording the interviews for the study and transcribing the interviews verbatim. This ensured capturing the participants' stories accurately. Feedback was requested from the participants in the study as well as the executive director, caseworker, and caseworker aide from the Lackawanna Blind Association. Feedback from the participants and workers allowed for triangulation between the researcher, participants, and workers.

## **CHAPTER FOUR**

### **RESULTS**

In this study, an occupational life consisted of human experiences in everyday activities: the roles, habits, and routines of the individual. This chapter presents the profiles of the participants' occupational lives, a vignette of the occupational lives of the participants, and the overall themes of the study. All of the day-to-day occupations and their associated interactions and strategies that promote an individual's adaptation, transitions, and overall participation in life are described.

#### **Profiles**

The researcher assigned participants with the pseudo names of Ann, Jane, and Joe. Below is the profile for each of the participants.

##### **Ann**

Ann is an 85-year-old retired office manager with macular degeneration who lives in a house in a suburb of the city. Ann worked for 27 years for the United Way of Lackawanna County. She retired from the position 10 years ago when she started having problems with her eyes. Prior to working for the United Way, Ann worked for Head Start and Bell Telephone.

Ann owns her house, and has lived in it for 30 years. Ann's house consists of a living room, dining room, kitchen, bathroom, two bedrooms, and a cellar. Ann's house is free of clutter, and the objects within the home have specific places and functions. Ann's cellar steps present as the only area of

concern within the home. The cellar steps do not have a railing and do not have overhead lighting. In addition, there is limited head clearance at the bottom steps. The environment outside the home consists of a front porch, back porch, gated yard, clotheslines in the back yard, and multiple sets of steps in the front yard. The steps from the street to the gated yard present as another area of concern for the home environment. The steps are uneven in height with one-step that is particularly high. All of the steps in the yard have railings on one side.

Ann is independent in most of her activities of daily living and instrumental activities of daily living. The only areas of difficulty for Ann are threading needles, reading recipes and/or package instructions, and using the microwave. Ann only identified being unable to read the Bible and/or standard print books; Ann listens to audio books. Outside of the home, Ann attends and participates in the Lackawanna Blind Association, the Ancient Order of Hibernians, the MAC club for her church, and mass on a weekly basis. Ann is highly motivated to participate in activities and to leave the home. Ann walks, uses private and public transportation, and also relies on friends and family to travel.

I like going downtown on the bus all alone. I love doing that. I love doing things on my own. (Ann)

Ann does not care what people are doing, if they ask her to go, she will go.

I am going. I don't care if it's a dog show. I'll go with them. It doesn't matter to me where I am going, I am going. (Ann)

Ann has strong familial support. One of her sons stops by her house every evening on his way home from work and on the weekends. She reports he



used to come twice a day, but she made him stop coming in the morning. Ann's daughter talks to her daily on the phone and takes her shopping on her day off during the workweek. Ann's other son, who lives in a neighboring state, calls her twice a week on the phone.

Ann was diagnosed with macular degeneration eight years ago. Ann has dry macular degeneration in one eye and wet macular degeneration in the other. Her eye doctor has been treating the eye with wet macular degeneration with injections. She receives the injections every eight or nine weeks. At the beginning of this study, Ann's intermediate visual acuity measured 20/200. During the final interview, Ann's intermediate visual acuity measured 20/160. Ann's visual acuity improved during the study. Ann's contrast sensitivity measured as severe visual impairment on the MARS chart during the initial interview. During the initial session, Ann was able to identify 39% of the items in the room. Ann successfully identified objects on the walls and stations in the room. Ann's greatest challenge was identifying objects on furniture and on bookshelves.

Ann has not received rehabilitation for her visual impairment. Ann's doctor has prescribed her with eyeglasses, and she has an over the counter magnifier and closed-circuit television. She also has a typoscope, 20/20 pens, and a digital device to read books on tape. Ann uses task lighting in her living room, kitchen, and her workstation in the dining room. She even added small lights on the side of the steps to the cellar. Ann's days, weeks, months, and seasons are structured and routine. Ann attends clubs on certain days and completes specific

chores at particular times on specified days. She also employs multiple strategies to remain independent.

I use magnification most of all, but I do use different strategies and at one time organization was really my best suit, I don't say it is any more, but I do the best I can, I try to keep things organized because it is easier to handle things if they are organized. (Ann)

### **Jane**

Jane is an 87-year-old homemaker with bilateral corneal transplants and glaucoma who lives in an apartment in a suburb of the city. Jane worked as a sewer in a factory while her first husband fought and died in World War II. Jane remarried and worked again outside of the home while her daughters were in high school and college to earn money to help pay their tuition. She stopped working after her second husband sustained a massive heart attack.

Jane rents an apartment across the street from her oldest daughter, and has lived in it for almost six years. Jane's apartment consists of a living room, dining room, kitchen, bathroom, and two bedrooms on the second floor of a home. Jane's apartment is immaculate and free of clutter, and the objects within the home have specific places and functions. Jane's flight of steps to her apartment present as the only area of concern within the home. While the stairs have good lighting and railings on both sides, the flight of steps causes Jane to become short of breath. The environment outside the home consists of a front porch, a set of steps into the front yard, and a concrete path to the sidewalk. The steps have a railing on both sides. The only area of concern is the uneven grass from the sidewalk to the street that Jane has to cross when leaving and returning home.

Jane is independent in her basic activities of daily living, but experiences difficulty with feeding and slicing. Jane's daughters complete her clothing care, shopping, meal preparation, and financial management. Jane is unable to write and read print, but enjoys listening to digital books and books on tape, and the television. Jane organizes things that she needs her daughters to do on the dining room table. Outside of the home, Jane attends and participates in the Lackawanna Blind Association, her town's senior citizen group, which meets one or two days a week, and church on a weekly basis. Jane is highly motivated to participate in activities and to leave the home. Jane's family and friends provide her with transportation and she rides the Lackawanna Blind Association's van.

I just participate in everything. (Jane)

Jane does not care what people are doing, if they ask her to go, she will go. "Well whatever is on them days, I'm there, I'm fine, right there, take me. I am ready to go." (Jane)

Jane has extremely strong familial support. Jane's oldest daughter lives across the street from her, prepares her meals, and eats dinner with her every day. Her daughter calls her multiple times a day to check in with her. Jane's other daughter lives in a neighboring town and talks to her daily. Jane's granddaughter and great-granddaughter see her weekly. Her granddaughter handles all of her bills. Jane is also physically and emotionally close with both of her grandsons and sees them on a regular basis. Jane and her children and grandchildren all vacation together and spend a lot of time with each other.

Jane received her first corneal transplant 34 years ago, and then received her second corneal transplant a few years later. Her doctor also diagnosed her glaucoma in both eyes. At the beginning of this study, Jane's intermediate visual acuity measured 20/1000. During the final interview, Jane was unable to see the visual acuity chart. She was only able to identify large objects in the room. Jane's visual acuity decreased during the study, and she saw her eye doctor during the study. Jane reported that her eye doctor did not know why her vision was rapidly deteriorating. Jane's contrast sensitivity measured as profound visual impairment on the MARS chart during the initial interview. During the initial session, Jane was able to identify 3% of the items in the room, and was aware of 18% of the environment. Jane successfully identified large objects on the walls, but did not notice the thermostat, electric outlets, the doorstopper, and a small plaque. Jane's greatest challenge was identifying stations in the room, objects on furniture, and objects on the bookshelves.

Jane received a few sessions of orientation and mobility last summer. She wanted to be able to walk to her cousin's house, which is up the block from her. Other than that training, she has not received rehabilitation for her visual impairment. Jane's doctor has prescribed her with eyeglasses, and she has a closed-circuit television. She relies on digital and tape machines which play books on tape for her. Jane's days, weeks, months, and seasons are structured and routine. She attends clubs on specific days and completes activities with her family at specified times on those days. Jane employs multiple organizational and memory strategies to remain independent.

Memory is mostly what I do things a lot by any more. (Jane)

## **Joe**

Joe is a 65-year-old retired salesman with genetic deterioration of the retinas who lives in a house in the city. Joe worked for 35 years for a pest control company. He retired from the position 10 years ago when he started having problems with his eyes.

Joe and his wife of 41 years own their house, and have lived in it for 40 years. Joe's house consists of a living room, dining room, two kitchens, two bathrooms, three bedrooms, a computer room, and a cellar. Joe's house is free of clutter on the floors, but does have piles of items in the dining room around the edge of the room. Joe has objects within the home in specific places based on their functions. Joe's dog presents as the only area of concern within the home since the dog is dark in color and the floors are dark in color. Joe has placed mats on the floor with contrast in areas where the dog typically lies down. The environment outside the home consists of a front porch, side porch, gated yard, sidewalks, driveway, and garage. The steps from the street to the front porch do not have a railing. The steps to the side porch have a railing on one side. An area of concern outside of the home is the front porch, which does not have railings. It is a couple of feet off the ground.

Joe is independent in most of his activities of daily living and instrumental activities of daily living. The only areas of difficulty for Joe are reading recipes and/or package instructions, using the burners, shopping, playing games, and writing. Joe's wife does the clothing care and financial management. Joe is

unable to read the telephone directory and uses his computer, scanner, and app reader to read items. Joe listens to books and magazines on digital and tape devices. Outside of the home, Joe attends and participates in the Lackawanna Blind Association, the Lions Club, the Veterans Affairs, and the Gino Merli Center. Joe is highly motivated to participate in activities and to leave the home. Joe travels by car with his wife and on various forms of transportation provided by the Veterans Affairs.

I feel that I'm a go-getter and I love to do things and you know as far as traveling as I mentioned before, if I had to crawl I'm still going to travel. (Joe)

Joe has strong familial support. Joe lives with his wife. His wife provides his primary mode of transportation. Joe also has a son and granddaughter. Joe has a close relationship with his granddaughter.

Joe's doctor diagnosed him with genetic deterioration of the retinas 10 years ago. Joe's vision has remained somewhat stable over the past 10 years. Joe's intermediate visual acuity measured 20/500 both at the beginning of the study and at the final interview. Joe's contrast sensitivity measured as severe visual impairment on the MARS chart during the initial interview. During the initial session, Joe was able to identify 18% of the items in the room, and was aware of 19% of the environment. Joe successfully identified objects on the walls and some of the stations in the room. Joe's greatest challenge was identifying objects on furniture and on bookshelves.

Joe has received extensive rehabilitation training from the Veterans Affairs for his visual impairment. Joe's doctor has prescribed him with eyeglasses. Joe

has had four formal training periods at two different Veterans Affairs facilities where he received training in orientation and mobility, computers, and arts and crafts. Joe has received numerous optical devices (two closed-circuit televisions, magnifiers, TV glasses), a talking glucose meter, digital and tape devices for books on tape, and a scanner. Joe has pill containers, a machine to read his prescription labels, and task lights. Joe uses task lighting in his computer room, and the kitchen. Joe's days, weeks, months, and seasons are structured and routine. Joe attends clubs on certain days and goes to the doctor on specific days. He also employs multiple strategies to remain independent. Joe enjoys using humor, organization, and technology to remain independent.

I'm definitely organized. (Joe)

### **Occupational Lives of the Participants: A Vignette**

The occupational lives of the participants consist of functional vision and knowledge to facilitate adaptation for participation. They use their remaining vision and draw upon knowledge from previous visual experiences as well as general knowledge to process their environments. Filled with constant challenges, they adapt to participate in everyday activities. They incorporate organization and routines to maximize their opportunities to participate in activities within the home and the community. Their motivation and drive creates an attitude of doing. Through participation in activities of daily living, instrumental activities of daily living, and leisure the participants strengthen their well-being and life satisfaction. The participation allows them to achieve their desired quality of life. They report happiness because of participation. The following

passages illustrate experiences and meaning from participation in their occupational lives.

I like going downtown on the bus all alone. I love doing that. I love doing things on my own, to be honest with you. I can go shopping, I can ride the bus, I walk, I go out to lunch, collect my diapers, and anything, anything that comes up I am happy to do. I do love to shop and I prefer to do it on my own. Sometimes I think I've modify things a lot that, that I am doing. So that I am not doing the same amount... that I did in the past. I enjoy doing that. The bus is two blocks from my house. I get the bus right from the Synagogue. I get off down town, and I make sure that when I am crossing the street that somebody else is crossing at the same time so I don't make any mistakes doing that. I think the most meaningful to me is going on my own. Whether it is walking or going shopping on the bus, you know, get on the bus and go some place, I think they're the ones that I enjoy. I love doing things on my own. (Ann)

I do what I want to do. I mean if I want to get something done. I try to do them, but I mean there is a lot of stuff that I go ahead and do. My eyes aren't that bad that I can't do what I really feel like I need to do sometimes. I mean there are things that I have to do. I dust, you know, I take a little duster and go around and dust a little bit. I'll clean it to keep it clean, but I don't really go scrubbing down any more. I don't do the really big cleaning things because I have the girl come in and clean for me. There is no mess to clean up, you just go back and put things back where they belong you know. You put them back where they belong when you put them down, you don't have to go back to them. So there is nothing much to do. I just kept going until I made sure that I got something that I wanted. I guess everything that I am doing is important to me because if I didn't have any of them I'd be unhappy. (Jane)

Well I knew that we were not going to eat for a while, so there was a restaurant there that had a line. I told him, you go ahead; I am going to wait on line. I don't want any cold sandwich out of a vending machine. So there was a line, but I waited and the line wasn't bad. So I said I am going to do it. So I just stood in line. When I got up to the thing, I heard the lady in front of me order spaghetti and meatballs for her son. I couldn't read the sign. So I



said, did I hear you say spaghetti and meatballs? She said yeah... When she gave me the thing, I said how do I get to the cash register. She was nice enough and said make a complete turn around and walk straight. There was a cash register there. My next challenge was to find an open chair, and like I said there was lots of people there and hardly any chairs. I just looked for chairs taking my time walking when someone yelled hey Joe, we have a seat for you right here. Then my son came in after his cold sandwich and couple of beers and I am sitting there eating spaghetti and meatballs with his friends from the wedding. He was a little jealous then I think. It was determination, I mean I was determined that I wasn't going to eat a cold sandwich and I was going to stand in that line if I had to. (Joe)

### **Themes**

Ann, Jane, and Joe live full productive lives. The themes of an occupational life of doing, an occupational life rich with well-being, and an occupational life filled with motivation for independence emerged from this study. The next sections explore the themes and reveal their stories.

#### **An Occupational Life of Doing**

AOTA (2014) describes participation as “involvement in a life situation” (p. S4). The participants’ occupational lives embody a life of doing. The participants engage in daily, weekly, monthly, and seasonal routines. The participants do not sit quietly in their homes. All of the participants complete their activities of daily living, participate in instrumental activities of daily living, and engage in leisure and social participation. The participants also engage in formal and informal volunteer activities. Participation in the activities provides the participants with meaningful experiences.

**Activities of daily living.** Successful completion of activities of daily living is the foundation of an occupational life. Individuals able to complete their basic needs facilitate basic survival and well-being (AOTA, 2014). In this study, Ann, Jane, and Joe were all reasonably independent in their activities of daily living. They independently completed their health-management and medication routines, and bathed, fed and dressed themselves.

**Medication routines.** During the full day observations, the researcher observed all of the participants taking their medications independently. Ann organized her medications in her kitchen. She had a shelf with her medications and vitamins. She lined up all of the pills and took them with her breakfast. Jane carried her medication in her purse and consumed the medication with her lunch while at the senior citizen center. Joe organized all of his medications and his blood glucose monitor in his kitchen. Joe had a tray with two different sets of pillboxes. Each set contained sleeves of containers for a week. Joe reported filling his containers weekly. Each day he would take out the sleeve of containers for the particular day. Joe lined up his medications at each meal and took the medications. Each of the participants developed a specific organizational strategy for taking their medication.

**Grooming.** When asked about grooming, the participants reported independence in grooming activities except toenail care. Each of the participants went to the podiatrist for their toenail care. Their medical insurance provided coverage every nine weeks.

I do everything but the toenails. I do everything independently except the toenails. The doctor does them for me. I'd rather do

them myself. Right now I am going tomorrow, and I could scream because they hurt. They get so long. Nine weeks in between, that's a long time. (Ann)

I don't do my finger nails and toenails, and I do everything else. (Jane)

I am a diabetic, I go to a foot doctor, and they trim my nails every nine weeks. (Joe)

**Instrumental activities of daily living.** Instrumental activities of daily living support participation in the home and community environments (AOTA, 2014). All of the participants in the study participated in instrumental activities of daily living. The participants engaged in some tasks and delegated some tasks to family members. The participants all addressed their roles and family members' roles in mending clothes and clothing care, meal preparation, financial management, reading, using the telephone, and community mobility.

***Mending and clothing care.*** For mending and clothing care, Ann, Jane, and Joe reported independence in using scissors, but only Ann participated in sewing and mending clothes and laundry. Jane and Joe both deferred those activities to their families. Ann reported modifying the activities due to her visual impairment while Joe reported completing laundry while receiving rehabilitation, but not while living with his wife.

I have a terrible time trying to thread a needle. I hem my pants with the glue now, the fabric glue, so I can do that, and I, I cut them off on my own, I wouldn't say I am perfect, but I do it. I don't know if I see that well that I iron everything perfectly, but I can get away with the way that I iron. Well I do, I love ironing. (Ann)

My daughter does all of my washing for me. I wish that I could do my own, but I mean, you know she lives right across the street. She takes mine when she does hers and does it up. (Jane)

When I was at the VA I had to do my own laundry, but at home, my wife takes care of it all. (Joe)

During the full day observations, the researcher observed Ann independently care for her clothes. Ann washed the clothes in the washing machine in her cellar; when the machine finished she carried the clothes upstairs in a bin and took them outside. Ann hung her clothes to dry on the clotheslines in her backyard. She slid the laundry basket along the ground with her foot as she pinned the clothes to the line. In the afternoon, Ann removed the clothes from the lines, and placed them in the basket. Ann then carried the basket down to her cellar to iron her clothes. As Ann ironed the clothes, she hung the clothes on hangers in her cellar. When she finished ironing, she carried the clothes upstairs and put her clothes away. During the full day observation of Jane, Jane's daughter brought Jane's washed clothes to her house in a bag. Her daughter then put the clothes away for Jane. Laundry was not observed at Joe's house.

***Meal preparation.*** Of the three participants, Ann participated and completed most of her instrumental activities of daily living independently or with some level of difficulty. Jane and Joe delegated a number of activities to their family members to complete. Ann completed her own cooking. Jane's daughter prepared or cooked meals for Jane on a daily basis. Joe fixed breakfast and

lunch for himself and his wife prepared dinners or took him out to eat. All three used organizational strategies and adaptations for the microwave.

I have a hard time setting the different temperatures on the microwave. So consequently I use the half minute automatic quick set. I use that. (Ann)

The microwave, I do that a lot. The settings I don't set it, you know what I do, I just push the one dial and let it go on one minute or two minutes, then I'll test it to tell if it is hot enough or cold enough. Well, it's not difficult cause I just turn that button on. (Jane)

Microwave...that is my specialty. I handle that with no problem. I had them set up the dots at two minutes, and I can go to one to three, so that works out good. I know where the start is and time. (Joe)

During the full day observations, the researcher observed all of the participants preparing at least one meal. Ann prepared three meals, Jane prepared one meal, and Joe prepared two meals.

The researcher observed Ann independently make breakfast, lunch, and dinner. Ann prepared cereal with fruit for breakfast. She independently retrieved the items from within her kitchen. She cleaned up the leftover items as she finished preparing her breakfast. For lunch, she sliced grapes and scooped watermelon into containers, and retrieved yogurt, crackers, and cookies in order to pack her lunch for the Lackawanna Blind Association. For dinner, Ann prepared a salad with lettuce, tomato, cheese that she sliced into cubes, shrimp she peeled, and a hard-boiled egg and grapes that she sliced. Ann then added salad dressing to the salad. Similar to breakfast and lunch, Ann returned the

items to the locations that she retrieved them from in order to prepare the meal at dinner.

Jane independently ordered sandwiches and chips from a nearby deli that delivered. Jane packed the sandwich, chips, and a bottle of water for her lunch at the senior center. Jane had already eaten breakfast when the researcher arrived. Jane reported eating cream cheese on graham crackers for breakfast. Jane ate dinner out with her daughter and great-granddaughter.

Joe independently made breakfast and lunch for himself. For breakfast, Joe made himself cereal and sliced fruit to put into the cereal. Joe lined the fruit up on the counter. He counted the pieces of fruit and sliced them on a napkin on his kitchen counter. After slicing the fruit, he placed it into his cereal. For lunch, Joe took out a microwavable lunch from his freezer and heated it in the microwave. Joe felt the bump dots on his microwave to select the settings to cook his meal. Joe also retrieved cookies from a cabinet and a jar to eat as dessert. Joe ate dinner out with his wife.

***Financial management.*** Ann completed her own financial management while Jane and Joe delegated the task to family members. Ann reported independently completing her own financial management using her closed-circuit television. Jane reported her granddaughter or daughter handled her financial matters and Joe reported that his wife handled his.

Fairly legible check writing, but I do my own finances. I am not the greatest writer, but I do it. The money I can handle independently.  
(Ann)

I don't [do] any of that, my other daughter does all of that. I know what is going on with them because she tells me, but I mean I don't look them up, she does it. She writes my checks all out. (Jane)

She pretty much handles all of that. No, I don't do any check writing. (Joe)

During the full day observations, the researcher observed Ann independently read her electric bill under the closed-circuit television. Ann then independently took out her checkbook from the drawer below the closed-circuit television and accurately wrote out the check to pay her electric bill. Ann used her closed-circuit television to place her typoscope on the check. Ann then looked at the typoscope as she filled in the section of the check. After completing the section, Ann looked back up at the closed-circuit television and placed the typoscope on the next section of the check that she wanted to complete. Ann repeated the pattern of placing the typoscope on the check with the closed-circuit television and then looking down to fill in the section of the check until she filled in all sections of the check. Ann then placed the bill and check into the envelope. Ann removed a stamp from her address book in the drawer below the closed-circuit television and placed the stamp on the letter. She also took out a return address label and placed it correctly on the letter. Ann returned the address book to her drawer and then took the letter and placed it in her mailbox, which was outside her front door.

**Reading.** All of the participants reported that they enjoyed reading. Due to their visual impairment, they adapted their method of reading. Jane and Joe found satisfaction with the adaptations and Ann did not.

Well, as I said the things that I love to do and do on my own that I really miss most on my own is reading. I love to hold the book and read it and I miss that, you know the tangible turning the pages and what have you. I miss that, so I am a different person there. I am sitting listening to tapes now falling asleep instead of being aware and awake and I have to go back and go over what I missed. I miss the reading of course. (Ann)

I play that reading book. I do read the books and I enjoy the books to read. (Jane)

I love to read. I read the paper all the time, books on tape, magazines on tape. Books on tape that is all I do. I have a scanner that I scan the paper into my computer and then the app reader reads the page. That is all audio too. I have four or five magazines on tape. (Joe)

During the full day observations, the researcher observed Ann and Joe reading. Ann took out her hand-held magnifier and turned on her task light in her living room. Ann used the lighting and the magnifier to read her prayer card. The researcher also observed Ann reading her electric bill with her closed-circuit television at her workstation in her dining room. Ann independently completed both reading tasks.

The researcher observed Joe reading the daily newspaper. Joe needed his computer and scanner to read. Joe independently turned on his scanner and his computer. Joe placed the page of the newspaper that he wanted to read on the scanner. Joe then opened the scanned document in Microsoft® Word. Joe pressed the app reader button on his high-contrast keyboard, which then read the document to Joe. Due to the size of the newspaper page, Joe needed to scan each page of the newspaper four times to cover all of the materials on the page. Joe read



the front page of the newspaper, the third page, and the obituaries independently.

**Telephone.** All of the participants reported independently using the phone to make and receive calls. Ann reported using the phone independently without assistance while Jane and Joe reported using directory assistance for making phone calls.

I'm very familiar with it. I do it very well, I don't like talking on it, but other than that, I can handle it. (Ann)

I use the directory for getting me numbers. I do use that a lot. I use that a lot. I'm independent in calling them to get it for me though. (Jane)

Most of the time I have to use directory assistance. I do excellent on answering the phone, but I don't do excellent on dialing it. I love to receive calls, but very rarely do I make calls. (Joe)

During the full day observations, the researcher observed all of the participants independently make and receive telephone calls. All of the participants had large print phones. The participants communicated with family and friends on the phone. They used the telephone to arrange for transportation, to order food, and to schedule social events with family and friends.

**Driving.** All of the participants reported having to give up driving because of their visual impairment. Ann stopped driving four years ago, Jane stopped six years ago, and Joe stopped ten years ago. For the participants, arranging transportation took organization and a network of resources. All of the participants took the Lackawanna Blind Association's van when it was available to travel to and from the center. Ann also used the county van, public busing,

family and friends' cars, and walked to places that she needed to go. Jane mainly relied on family and friends' cars for transportation. Joe relied on his wife driving, and used the transportation provided through the Veterans Affairs. All of the participants planned and organized their transportation in order to participate and complete activities outside of the home.

I walk, I like to walk, and I manage that very well. I like to go to town on the bus. If I have doctor's appointments I go on the van, the van takes me and picks me up. Going to church as I said to you, if my friends go or if they don't go, my son or my daughter or somebody else will always be available to take me. I have these times that I have walked to a church that is not too far from my house, and I, well that's how I get around. (Ann)

I go out of my home every day. I visit my cousins, I might go to my cousin's house or my daughters might take me up to a hospital to see somebody that's in the hospital. I travel all the time in the car. I don't go on the buses. Wherever I go during the day, it is either one of my daughters that take me or else one of the neighbors. I go with the neighbor or else my cousin might pick me up. Car is my travel. (Jane)

Mondays I go to the VA, the only two days that I can go to the VA is Monday and Wednesday because I go on the DAV van and that is the only two days that they run. So I try to keep Mondays and Wednesdays open for the VA. You just make a call and let them know that you have an appointment; they'll check that you have an appointment and then it picks you up at 8:30 in the morning and then brings you back around 12:30 in the afternoon. I'm going to see my financial advisor with my wife tomorrow and then right after that she is going to drop me off for lunch. Then she will pick me up and bring me back home. I used to use the van all of the time, but then when my wife left her job, and then now I use her as my chauffeur. (Joe)

During the observations at the Lackawanna Blind Association and the full day observations, the researcher observed all of the participants travel outside of the home.

During the observations at the Lackawanna Blind Association, Ann traveled to the center on coordinated transportation through the county and Lackawanna Blind Association's van. Ann had called and scheduled the county van to pick her up and take her to the Lackawanna Blind Association. She returned home on the Lackawanna Blind Association's van. Jane traveled to and from the center on the Lackawanna Blind Association's van. Joe traveled to and from the center in his wife's car. The researcher observed Ann receiving assistance onto the Lackawanna Blind Association's van by the driver and Jane receiving assistance getting off and onto the van by the driver. All of the participants were independent in putting on their seat belts.

During the full day observations, Ann traveled to the Lackawanna Blind Association on coordinated transportation through the county and home on the Lackawanna Blind Association's van. Jane traveled in her neighbor's car to the senior citizen center, and another neighbor brought Jane home from the senior citizen center. Later in the evening, Jane's daughter took Jane out for dinner and to her great-granddaughter's baseball game. Her daughter then brought her home after the game. Joe traveled in his wife's car to dinner and returned home with her after dinner. All of the participants independently entered and exited the vehicles that

transported them from their homes into the community and back. The participants reported that they learned how to rely on private and public transportation in order to participate in activities in the community.

***Functional mobility.*** All of the participants reported independence in functional mobility. They also reported independence on stairs. Jane reported the need for a good railing and Joe reported the need for good contrast. All reported independence in avoiding trips and falls. Ann and Joe reported independence negotiating curbs while Jane reported difficulty. Joe was the only participant with a white cane. He reported only using it in unfamiliar environments.

During the full day observations, all of the participants independently ascended and descended stairs. Ann independently navigated into the community without assistance. Jane's daughter and granddaughter served as sighted-guides for Jane to travel to a restaurant and to a baseball field. Joe independently navigated from the car to a restaurant and back without his cane or a guide.

**Leisure and social participation.** Leisure and social participation provide individuals with opportunities for intrinsically motivating activities that support engagement in the community with family and friends (AOTA, 2014). For the participants in the study, this meant participating in activities with friends and family. All of the participants belonged to the Lackawanna Blind Association as well as other community groups. Ann belonged to the Ancient Order of Hibernians (AOH), her church's social group (MAC club), and her church. Jane

belonged to her town's senior citizen center and her church. Joe belonged to the Lion's Club, and the Veterans Affairs support group. All of the participants attended weekly and monthly meetings with the groups. The groups provided happiness and socialization for the participants.

Once a month on Thursday, I got to the AOH. I go to church every Sunday, and if there are church activities within the week, I do that. Well, I told you about calling people and making the reservations for the AOH; I like that club very much and then I take the money and take the reservations as people come in. I do that. I do like going to lunch. It means a lot to me, it means getting out of the house. It means associating with other people. (Ann)

I go over to the senior center. Oh I do, and we have a good time with them, we have a good time. We eat and we talk. I just go and sit there and gab with them just like anybody else does. (Jane)

I belong to the Dunmore Lions Club, I have been with them maybe 25-30 years also, and we have two meetings a month. Just a regular meeting, and then we have a little club house up at St. Anthony's Park up in Dunmore. We meet there for the regular meeting and then on the second meeting of the month, we have a dinner meeting. We go to different restaurants in Dunmore, we have a meal, and then we have our meeting. I love the social part of it, you know, I just love being with people. (Joe)

The researcher observed all of the participants at the Lackawanna Blind Association, and during the full day observations the researcher observed Jane attending the senior citizen center.

At the Lackawanna Blind Association, Ann and Jane participated in the life skills and exercise class. Both Ann and Jane independently completed the exercises that the instructor instructed the group to complete. Ann reported listening to the instructions and watching the group. Jane reported she listened

to the instructions. The researcher observed Ann and Jane successfully complete the exercises. At the center, Ann traveled independently throughout the center and Jane required a sight-guide to travel. Ann and Jane interacted with the group during lunch and the researcher observed them having a good time.

At the Lackawanna Blind Association, Joe participated in the Shopland Club. On the day of the observation, the researcher observed Joe participating in all of the club's activities independently. Joe paid for his lunch and gave money to the kitty. Joe said the Our Father prayer, the pledge, and sang the Star Spangled Banner at the beginning of the meeting with the group. During the meeting, Joe made motions and the group elected him to the position of assistant treasurer for the group. After the meeting, Joe independently ate his lunch and interacted with the group. Joe traveled independently throughout the room without his white cane. The researcher observed Joe having a good time with the group.

During the full day observations, the researcher observed Jane at the senior citizen center. Before the meeting, Jane's neighbor who lived below her walked up the stairs to let her know that he had the car outside in front of the house. Jane independently gathered her lunch and belongings, and locked up her apartment. Jane independently went down the stairs and entered her neighbor's car. When they arrived at the center, the neighbor dropped Jane off outside the building. Jane reported that normally she would have waited for the neighbor to park before entering the building. Due to the construction outside the

building, Jane asked the researcher to guide her to the building. Jane independently followed the researcher to the building. Once in the center, women at the front table guided Jane to her table. Jane sat down at her seat at the table, gave one of the women money for the raffle, and later gave her money for the lottery that she specifically placed in certain compartments of her wristlet prior to leaving her home. Jane sat at the table and said hello to the people at her table as they arrived to the table. Other members of the senior citizen center walked up to Jane and said hello to her. Jane participated in the prayer before lunch and then ate her lunch. Jane asked her friend to cut her sandwich in half for her since it was more than she wanted to eat. Jane ate half of the sandwich and wrapped the remaining portion of the sandwich to take home. Jane chatted with her friends at the table until the President called the meeting to order. Jane listened to the reports given by the members. At the end of the meeting, one of Jane's neighbors told Jane he was ready to drive her home. He guided her to the car, and Jane independently got into the car and fastened her seatbelt. When they arrived at her house, Jane thanked him, independently left the car, and entered the house.

***Traveling.*** All of the participants also reported their love for traveling. Ann travels with friends on vacation with her church group. Jane and Joe travel with their families on vacation. They all reported that they find vacation enjoyable and have a great desire to travel.

I belong to a MAC club and actually, that is a lot of participation. It is more than worth the work that I put into doing it. Luncheons, what have you, looking forward now every year we go to the shore

the last week in October and bus trips here and there. I enjoy being with people my own age. I enjoy all of their company. (Ann)

We go on vacations. I still go on vacations with them. Vacations are important. I do everything that they are doing, wherever they go, I go. (Jane)

I love going places and doing things. I feel that I'm a go getter and I love to do things and you know as far as traveling as I mentioned before, if I had to crawl I'm still going to travel. (Joe)

**Formal and informal volunteering.** Volunteer activity provides the opportunity to support individuals and societal causes. For the participants in the study, volunteer activities provided a sense of purpose and an opportunity to socialize with others. Ann reported volunteering to collect diapers for a local center. She also reported volunteering for the AOH where she organizes the reservations for their meetings and collects the members' money for lunches at the events. Jane reported volunteering to say a prayer for the senior citizen center and volunteering to speak at her church. Joe reported serving on the board of directors at the Gino Merli Center. In addition to serving on the board, Joe reported volunteering and meeting with veterans on a weekly basis.

I collect diapers to donate to St. Joe's. Some of my friends and my family are the donors. I go around and collect my diapers if they don't bring them to me. The few people that I do it with, I had a whole lot more on my list, except that they all died on me (laugh). I belong to the Ancient Order of Hibernians, and I take the reservations, call people, take their reservations, take all of the callbacks, reserve the Coopers for the day. Then I take care of the money when they bring it, you know when they pay for the reservation on the day of the meeting, those are the two things that I am most active in now. (Ann)



I go over to the senior center. Although I do say the prayer, I mean they have people to say a prayer every day. At the beginning of the year, they go around and anybody can sign it, and they'll ask if you want to sign it and stuff. So that's the only thing that I do. Church has always been a big thing for me. They still use me. They asked me yesterday to say the prayer there. So they still call on me to do stuff. I am always there when anything is going on in church. I think I would feel bad if I couldn't go to church, but I mean I make it to church, I get there all the time. (Jane)

I just started volunteering at Gino Merli Center and I am active with the Blind Veterans Association, and active with the VA. The majority of the things that I have been doing is socializing with the veterans, I would have a list of veterans that they want me to see, and then I would go sit down with them and talk. Talk to them about their military career, or what they did when they were working, or where they live, and talk about their neighborhood a little bit, what they like to do. Sometimes they're family. It is a social type of situation. (Joe)

For the participants, their occupational lives consisted of doing. From activities of daily living in the home to socialization and participation in groups in the community, the participants have created routines that support their participation. Daily habits and routines provided a structure to enable participation. Strong family and friend support provided a network of individuals who are available to assist with transportation needs for participation in the community. All of the participants have organized their homes in a way that allows them to remain reasonably independent in the home. Joe was the only participant who faced challenges with the organization in the home. Joe reported that his wife and granddaughter move things from their specific locations in his home creating a challenge for him. For the participants, engagement and doing created happiness and wellness.

## **An Occupational Life Rich with Well-being**

AOTA (2014) describes well-being as “a general term encompassing the total universe of human life domains, including physical, mental, and social aspects” (p. S4). For the participants, their occupational lives embody a life rich with well-being. Support from family and friends enhanced participation and well-being. All of the participants rated their overall quality of life as good and their happiness as an eight or a nine on a scale from one to ten.

**Support from family and friends.** All of the participants reported strong support from their family and friends. The lowest rating from the participants on the MOS Social Support Survey was support “some of the time.” The participants had emotional and informational support “most of the time.” Tangible support and affectionate support for the participants ranged from “some of the time” to “all of the time.” Positive social interaction and someone to help get their minds off things ranged from “most of the time” to “all of the time.”

Well, I have a daughter nearby and a son nearby. My son stops in every single day, my daughter calls just about every day, and I have another son that calls at least twice a week. My son usually comes in after work, and we'll have a chat for as long as much time as he can spend with me. I go shopping every Wednesday with my daughter, and I get out in between with my granddaughter. Well, my daughter is wonderful for she takes me every week and spends her day off with me. I have a friend that is still driving, which is very few of them left that are driving. Like on mass on Sunday morning, if my friends aren't going, then my son will come and take me and as I said my daughter comes on Wednesday, it's her day off. That kind of bothers me you know, that she gives up her time. Anyhow, we are doing it and she usually has a whole day off. Now this week she told me she thought she might have to work in the morning. So we would be going in the afternoon, but we do make arrangements ahead of time. When I have to go to Dr. Paris, you have to have

somebody there to drive you, so my daughter takes me there or my granddaughter, or if both of them are tied up my son will take me.  
(Ann)

So my life is unique that I can have daughters that make my life as beautiful as it is, that is all that I can say about it. First of July, we are all going down and we are all going to be in a cottage that we rented. So I mean, you know, we are family and we do a lot of stuff together. I am not in the house day after day after day after day. I mean, my kids make sure that I go with them wherever we are going. And my granddaughter now, I don't think, maybe she'll be playing a game, I'll take ya to the game tomorrow night if she is working at the game, but I mean she is only 5 years old, she is in that little, that little league thing. We go to that and that is twice a week that we go to that. We're a close family. My daughter does all of my washing for me. It is very nice and it is very nice, and that is why even my suppers are done over there too, so she makes everything there and puts it right down there for me. I don't fix meals that much, you know, really make them. Because if my daughter is going to be out she'll give me something to eat at night anyway. My daughter comes home from work, she calls me when she is starting to get supper going and I go over there for supper. And then, wherever I go during the day it is either one of my daughters that take me or else one of the neighbors, like I go with the neighbor or else my cousin is going, she might pick me up. So I mean, somebody always makes sure that I get to church. If my girls can't take me because my daughter works on Sundays, my other cousin comes and picks me up and she drives me to church.  
(Jane)

I have been married for 41 years so, I have one son, I have a granddaughter who is 11 and she is going to be 12 in the end of August. At home my wife takes care of it all. [In regards to support] Yeah, again it would be my wife, or you know my son, or granddaughter. I mean, I can say all of the time, but I mean, I mean I live with my wife, and my wife might go out with a friend or something, I hate to keep repeating myself, [I have support] most of the time. I think I already told you that story about the one time when I, when I thought, you know, that I was getting my vision back. Because it was right before we were in New York and I

tripped over a curb because I didn't have my cane with me and I fell down and my granddaughter was with me. And God, she helped me up and that the whole time we were in New York she wouldn't let my hand go. Then she, you know, she stayed right with me.  
(Joe)

For the participants, support from family and friends provided means of well-being. The participants had family and friends to call on for everyday needs and emergencies. None of the participants had to worry about who was available to assist them if needed. During the full day observations, all of the participants interacted with at least two family members during the day. Ann's son and daughter visited her in the afternoon. Ann's son came over to put the air conditioner into the window for Ann, and her daughter brought over some groceries for her. Jane's daughter, great-granddaughter, and grandson visited her during the day. Her daughter and great-granddaughter took her out to dinner and then took her to the great-granddaughter's baseball game where her granddaughter met her. Joe had his wife and granddaughter at his house in the early morning. They then left to go shopping. Joe's wife returned in the early afternoon and then took Joe out to dinner. Throughout the full day observations, family and friends called the participants. The participants had access to family and friends.

### **An Occupational Life Filled with Motivation for Independence**

Occupations are goal-directed activities that provide meaning to individuals (AOTA, 2014). The participants filled their occupational lives with desire, a drive to problem solve everyday activities, and the will to remain independent in everyday activities. Each day, the participants faced the

challenge of not having the visual input that they once had to complete their activities. The participants felt an intense drive to remain independent and to complete activities on their own. It did not matter how small or how large the task, they wanted to do it on their own.

I mean you make your own happiness. I like going downtown on the bus all alone. I love doing that. I love doing things on my own, to be honest with you. I can go shopping, I can ride the bus, I walk, I go out to lunch, collect my diapers, and anything that comes up I am happy to do. I do love to shop and I prefer to do it on my own. I think the most meaningful to me is going on my own, you know, whether it is walking or going shopping on the bus, you know, get on the bus and go some place. I think they're the ones that I enjoy. I love doing things on my own. I work it out the best of my ability. If it is something that I need to see, if I am in the kitchen and I was trying to read something there, and I couldn't read it with the magnified glass in the kitchen, I would go into the living room under that lamp that I can read. Or under the machine or trying to read a recipe or something like that. I try to do the best that I can, you know, with what I have. I take charge, that is hard to give up too (laughing). I do things slipshod, but I am not giving it up. It depends upon, it depends upon how much I want to do it, you know, the intensity that I feel that I want to do, that is the overriding factor. I get it done one way or the other, I'll make sure I get it done, maybe not perfect, but I'll get it done. Doing things my way. I don't know if I have any strategies, I just do things. The will to do it, want, want to do it, to want a sense of accomplishment, and, you know, to be with people and to just want to do and take part in things that they are doing. I would like to be able to do it all, and I try darn hard. (Ann)

I just participate in everything. Well whatever is on them days, I'm there, I'm fine, right there, take me. I am ready to go. I guess everything that I am doing is important to me because if I didn't have any of them I'd be unhappy. I do what I want to do, I mean if I want to get something done. Well I try to do them, but I mean there is a lot of stuff that I go ahead and do. I said my eyes aren't that bad that I can't do what I really feel like I need to do sometimes. I

mean there are things that I have to do. Well I just kept going until I made sure that I got something that I wanted. (Jane)

Well I knew that we were not going to eat for a while, so there was a restaurant there that had a line. I told him, you go ahead; I am going to wait on line. I don't want any cold sandwich out of a vending machine. So there was a line, but I waited and the line wasn't bad. So I said I am going to do it. So I just stood in line. When I got up to the thing, I heard the lady in front of me order spaghetti and meatballs for her son. I couldn't read the sign. So I said, did I hear you say spaghetti and meatballs? She said yeah... When she gave me the thing, I said how do I get to the cash register. She was nice enough and said make a complete turn around and walk straight. There was a cash register there. My next challenge was to find an open chair, and like I said there was lots of people there and hardly any chairs. I just looked for chairs taking my time walking when someone yelled hey Joe, we have a seat for you right here. Then my son came in after his cold sandwich and couple of beers and I am sitting there eating spaghetti and meatballs with his friends from the wedding. He was a little jealous then I think. It was determination, I mean I was determined that I wasn't going to eat a cold sandwich and I was going to stand in that line if I had to. (Joe)

The participants had a desire to do something and achieved their goal of completing the task. Ann loves to travel into the city on the bus to shop. She continues to travel on the buses alone despite her children being unhappy with her doing it. Jane also likes to do things her own way. She reported that she enjoys being able to do things on the days that she wants to. Her daughter wants her to go to the Lackawanna Blind Association multiple days a week. Jane told her that she has tasks around the house that she likes to complete on the days that she does not go into the community. Joe also loves to do the things that he wants to do. Joe loves listening to music on the internet. He plays songs on YouTube through headphones while his wife is home because she does not

like the noise. When she left the house, the headphones came off and he turned up the music. For the participants, their goal was to complete activities that they wanted to. The participants did what they had to do in order to be able to complete the activities that were most meaningful to them. Whether their family approved or not, they did what they wanted to do.

## **CHAPTER FIVE**

### **DISCUSSION**

The occupational lives of the participants revealed lives of doing, well-being, and motivation for independence. Through adaptation, organizational strategies, memory, and problem solving skills the participants achieved relative mastery of their occupations. This chapter will address the findings of the study as they relate to the theory of occupational adaptation, previous literature, their unique contribution to the fields of occupational therapy and occupational science, clinical implication, limitations of the study, and direction for future research.

#### **Support of Occupational Adaptation Assumptions**

The concept of occupational adaptation (OA) underpinned the study. The study's findings supported the assumptions and constructs of OA. The researcher focused on individuals with visual impairment, their occupational environments, and the interactions between the individuals and their occupational environments. When the participants' abilities and the occupational environment's demands matched, the participants achieved relative mastery. When the participants' abilities did not match the occupational environment's demands, press for mastery occurred.

The findings of the present study support Schkade and Schultz's (1992) most important assumption of the model that occupation provides the mechanism



for persons to adapt to change. The person's intrinsic desire to participate in occupation led to his or her adaptation. For the participants in the study, this assumption held true. All of the participants reported and were observed completing desired occupations using adaptive strategies. The participants adapted occupations in order to participate in them. During periods of transition, the participants called upon previous knowledge and different strategies and methods when encountering an activity that created an occupational challenge. The participants used previous knowledge to adapt to meet the needs of the challenge and successfully complete the activity or task. The participants achieved relative mastery of their occupations, the overall goal of the model.

### **Findings in Relation to Previous Research**

The findings of the present study partially support and partially contradict Rudman et al.'s (2010) findings that older adults with visual impairment who did not seek rehabilitation experienced an enhanced sense of risk. Although one participant in this study received comprehensive rehabilitation for his visual impairment, all three participants continued to participate in activities in the home and community environments, and two of the three participants had worse visual acuity than those in Rudman et al.'s (2010) study. The participant who received rehabilitation found the training beneficial for his participation in life. The two participants that did not receive comprehensive rehabilitation did not experience an enhanced sense of risk. The two participants continued to live active lives in the community.

The findings of the current study support the findings from studies on participation in occupations to promote health and wellness for individuals (Eakman, 2014; Eakman & Eklund, 2012; Hakansson, Dahlin-Ivanoff, & Sonn, 2006; Hammell, 2014; Hammell & Iwama, 2012; Reid, 2008; Stav, Hallenen, Lane, & Arbesman, 2012; Stevens-Ratchford, 2014; Wensly & Slade, 2012) that found participation in occupations promoted health and wellness. In addition, the current study supports the findings of previous studies on the act of doing (Bendixen et al., 2006; Eriksson et al., 2011; Erlandsson, 2013; Law, 2010; Persson, Andersson, & Eklund, 2011; Reid, 2011; Smith, Ludwig, Andersen, & Copolillo, 2009; Wilcock, 1999) that found doing allowed individuals to achieve a greater motivation for independence (Tay, Drury, & Mackey, 2014).

### **Unique Contributions to Occupational Therapy and Occupational Science**

Literature specific to the occupational lives of individuals with visual impairment is extremely limited. Literature exists on specific occupations, but does not address the individuals' occupational lives. This study presents the first available research on the occupational lives of individuals with visual impairment. The themes of an occupational life of doing, an occupational life rich with well-being, and an occupational life filled with motivation for independence revealed the participants' natural affinities for problem solving, the role of spirituality, and the importance of support from family and friends. The participants used adaptations, spirituality, and support to remain independent.

### **Problem Solving as a Strategy for Doing**

All of the participants in the study had a natural affinity for problem solving. All of the participants in the study continued to participate in activities in the home and community environments despite their visual impairments. Only one of the participants received comprehensive rehabilitation for his visual impairment, yet all three participants problem solved challenges and sought solutions to remain independent and participate in the home and community environments. The two participants that did not receive comprehensive rehabilitation for their visual impairment experienced changes in their visual acuity during the study. The changes to their visual acuity did not stop their participation in occupations and activities. The participants in the study were highly motivated to participate in occupations and activities in the community with their families and friends.

Good problem solving abilities allowed the participants in the study to participate in occupations and activities in the home and community environments. Through participation in these occupations and activities, the participants developed adaptations and strategies for doing. The participants incorporated different adaptations to maximize their participation. The participants organized items in specific locations, added lighting, and modified tasks to simplify the number of steps necessary to complete their occupations and activities. The participants also incorporated adaptive equipment into the occupations and activities to continue to participate in them. The repertoire of adaptations and strategies became part of the participants' habits and routines.

The participants verbally identified some of the adaptations and strategies while the researcher observed others during the observation sessions. The participants' problem solving skills allowed them to integrate the adaptations and strategies into their lives to the point where they no longer had to think about the adaptations and strategies while completing their occupations and activities. The participants were able to problem solve and do the occupations and activities that they wanted to do.

### **The Role of Spirituality**

Spirituality played a large role in the participants' abilities to accept their visual impairment. All of the participants expressed gratitude and thankfulness for the vision that they had left, and hoped that their vision would remain stable. They also reported asking God for help when they faced challenges. For the two female participants, spirituality was the major focus of their lives. Each week they would attend church service. They arranged with family and friends for transportation to church. One female participant reported that she would walk to church if she had to and the other female participant reported that she would be unhappy if she could not go to church. Their spirituality expanded beyond attendance at church. Both female participants were involved with volunteer activities at their churches. The male participant reported that he was Catholic, but stopped attending mass a long time ago. Throughout the interviews, he and the female participants expressed gratitude and thankfulness. The participants' faith and belief in God gave them comfort with their vision loss. A strong sense of gratitude and thankfulness was found across the participants.

### **Support of Family and Friends Enabling Well-being**

All of the participants in the study had strong support systems. The participants reported and the researcher observed strong support from family and friends. Two of the participants lived alone, yet had multiple family members visit them on a daily basis. Their scores on the MOS Social Support Survey indicated a strong level of support from family and friends. Even the participant that lived with his spouse had additional family members visit him. All of the participants received daily calls from family and friends checking on their well-being. The support of family and friends allowed the individuals with visual impairment to remain active in the community and to participate in multiple clubs or organizations in the community, which supported their well-being. The participants all reported their overall health and quality of life as fair to good and their emotional well-being between 8-9 on a scale of one to ten. Support from family and friends facilitated their independence in ADL, IADL, leisure, and social participation, which enabled their well-being.

### **Clinical Implications**

The findings of the study have several implications for clinical practice. Occupational therapists should ask their clients how they solve problems and the strategies they use when encountering a challenge. In addition, occupational therapists should observe their clients participating in occupations and activities.

In the study, participants integrated the use of strategies and adaptations to the point where they were no longer aware that they were using strategies and

adaptations. By observing clients participating in activities of daily living and instrumental activities of daily living, occupational therapists will gain insight into the strategies and adaptations already used by the clients. This will help occupational therapists to identify other possible strategies and adaptations that are not being used.

Occupational therapists should consider incorporating the strategies and adaptations of organization, task simplification, and adaptive equipment to promote independence in activities of daily living and instrumental activities of daily living. By organizing activities by room or task, clients will be able to efficiently complete occupations and activities. Through task simplification, clients will save time completing occupations and activities, and adaptive equipment will serve to compensate for areas of challenge.

Finally, occupational therapists should explore the level of support available to clients. Support from family and friends played an important role in facilitating participation in the community for the participants of the study. Occupational therapists should help their clients to identify support available through family and friends, as well as private and public organizations that support individuals with visual impairment. Support played a vital role in enabling well-being for the participants of the study. Family and friends provided the participants with readily available transportation on a regular basis. Family and friends also assisted the participants in their IADL. The families assisted with shopping, money management, clothing care, and home maintenance. Family and friends were available to the participants and offered assistance without

being asked. These findings support a systematic review of family functioning and low vision by Bambara, Wadley, Owsley, Martin, Porter, and Dreer (2009) which found that family play a unique role in providing instrumental and emotional support to individuals with visual impairment. Occupational therapists should explore their clients' support systems and the availability of support systems. Integrating supportive family and friends in the intervention process will maximize clients' abilities to participate in the home and community environments.

### **Limitations**

This study had several limitations. This study heavily relied on self-reported data for the participants. Quantitative measures and observation sessions were incorporated into the study to corroborate the accuracy of the self-reported data. The researcher observed the participants at the Lackawanna Blind Association, as well as observing each for a full twelve-hour day to check the accuracy of the self-reported data. In addition, the methodology used convenience sampling with a small N. The study examined the occupational lives of three individuals with visual impairment. As a result, generalizing the findings of the study requires great caution.

### **Direction for Future Research**

Researchers should continue to explore the occupational lives of individuals with visual impairment. This study identified adaptations and strategies used by three individuals with visual impairment. Future studies will provide clinicians and researchers with a greater understanding of the

occupational lives of individuals with visual impairment. The researcher recommends the use of quantitative and qualitative methodologies to provide the fields of occupational therapy and occupational science with evidence-based research to promote the independence of individuals with visual impairment in the home and community environments. The researcher recommends the following future studies.

Researchers should replicate the current study in a rural area.

Participants in the current study had access to private and public transportation made available in an urban environment. While only one participant lived in the city, the other two participants lived in towns surrounding the city. The participants were able to access transportation and services made available in an urban environment. The professions of occupational therapy and occupational science would benefit from research on the occupational lives of individuals with visual impairment in rural communities to gain a better understanding of their occupational lives.

The researcher also recommends increasing the N of the study in order to be able to generalize the findings. Since the study was conducted in an urban environment, it would be beneficial to continue the study in the current environment and/or recruit additional participants from similar urban areas. The fields of occupational therapy and occupational science would benefit from a large-scale study of the occupational lives of individuals with visual impairment.

Finally, the researcher recommends studying the occupational lives of individuals with visual impairment that do not participate in the community.



Studying the lives of individuals with visual impairment that remain at home will help occupational therapists and occupational scientists gain a better understanding of their needs and interventions, which would promote integration into the community environments.

## APPENDICES

**APPENDIX A**  
**IRB APPROVAL LETTERS**



**APPROVAL NUMBER: 14-A068**

To: Julie Ann Nastasi  
1426 Layton Road  
Scott TWP PA 18411

From: Institutional Review Board for the Protection of Human  
Subjects Elizabeth Katz, Member

Date: Monday, February 24, 2014

RE: Application for Approval of Research Involving the Use of  
Human Participants



Office of Sponsored Programs  
& Research

Towson University  
8000 York Road  
Towson, MD 21252-0001

t. 410 704-2236  
f. 410 704-4494  
[www.towson.edu/ospr](http://www.towson.edu/ospr)

Thank you for submitting an Application for Approval of Research Involving the Use of Human Participants to the Institutional Review Board for the Protection of Human Participants (IRB) at Towson University. The IRB hereby approves your proposal titled:

*The Occupational Lives of Individuals with Visual Impairment*

If you should encounter any new risks, reactions, or injuries while conducting your research, please notify the IRB. Should your research extend beyond one year in duration, or should there be substantive changes in your research protocol, you will need to submit another application for approval at that time.

We wish you every success in your research project. If you have any questions, please call me at (410) 704-2236.

CC: R. Stevens-Ratchford  
File



March 19, 2014

To: Julie Ann Nastasi  
Dept. of Occupational Therapy & Occupational Science  
Modifications to TU IRB project 14-A068

Dear Ms. Nastasi:

Thank you for informing the Towson IRB of your modifications to project 14-A068 "The Occupational Lives of Individuals with Visual Impairment".

The Towson University Institutional Review Board for the Protection of Human Participants has reviewed and approved your modification for this project. However, this modification approval does not change the expiration date of the original approval, which will need to be renewed one year from the date of approval if the research is ongoing.

If any other modifications are made to this project, or if any new risks are discovered, please inform the Board immediately.

Should you have any questions, please do not hesitate to contact me at 410-704-2236.

Sincerely,

A handwritten signature in blue ink, appearing to read "V. Denise Spears".

V. Denise Spears, MPA

Compliance Administrator, On Behalf of Towson University Institutional Review Board for the Protection of Human Participants

CC:

R. Stevens Ratchford (Occupational Therapy & Occupational Science)  
File

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**MEMO**

To: Julie Nastasi  
From: Dr. Renée M. Hakim, OT/PT DRB Chair  
RE: OT/PT DRB Application #1402  
Date: March 10, 2014

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The requests and clarifications for your application were received and reviewed. Your project titled, "The Occupational Lives of Individuals with Visual Impairment" is now approved by the Occupational and Physical Therapy Department Review Board (OT/PT DRB) for a period of one year.

You may now begin your research project. Congratulations and thank you for submitting your application.

**APPENDIX B SELF-REPORT ASSESSMENT OF FUNCTIONAL VISUAL  
PERFORMANCE PROFILE VERSION C**

## Self - Report Assessment of Functional Visual Performance Profile Version C

Name: \_\_\_\_\_

Therapist: \_\_\_\_\_ Date: \_\_\_\_\_

Directions: Ask the client to rate ability to perform each task using the rating scale. Circle the number that best fits the client's ability.

1 = Unable: dependent on others to perform task; would perform task if able

2 = Difficulty: performs task with difficulty even under optimal conditions; difficulty performing task in a timely manner; safety & efficiency questionable; makes errors

3 = Independent: experiences no difficulty performing task safely, accurately, efficiently

NA = Not applicable or the client does not perform this task

Item	TASK DESCRIPTION	Rating
<b>PERSONAL CARE</b>		
1	Health Management - self-management and medication routine	1      2      3 NA
2	Personal Hygiene - grooming	1      2      3 NA
3	Feeding - locates food, seasons, spreads toppings, cuts	1      2      3 NA
4	Dressing - locate, identify and match clothing	1      2      3 NA
Comments:		
<b>CLOTHING CARE</b>		
5	Clothing Care - mending: thread needle, uses scissors	1      2      3 NA
6	Clothing Care - laundering: set dials, measure soap, treat stains	1      2      3 NA
Comments:		



MEAL PREPARATION				
7	Meal Preparation - read recipes, package instructions	1	2	3 NA
8	Meal Preparation - use oven - transfer food, monitor temp and time	1	2	3 NA
9	Meal Preparation - chop, slice, cut, peel; use knives safely	1	2	3 NA
10	Meal Preparation - pour/measure liquids and dry ingredients	1	2	3 NA
11	Meal Preparation - use burners: set dials, transfer items	1	2	3 NA
12	Meal Preparation - use microwave oven: select settings, transfer	1	2	3 NA
13	Meal Preparation - locate/organize items in kitchen	1	2	3 NA
Comments:				
FINANCIAL MANAGEMENT				
14	Financial Management - manage financial records	1	2	3 NA
15	Financial Management - read bills / financial statements	1	2	3 NA
16	Financial Management - write check / money order	1	2	3 NA
17	Shopping - locate and pay for item, manage money, make change	1	2	3 NA
Comments:				

USING TELEPHONE			
18	Retrieve telephone numbers - familiar and unfamiliar	1	2 3 NA
19	Physically operate telephone: dialing	1	2 3 NA
Comments:			
LEISURE			
20	Leisure Participation - other leisure activities important to client	1	2 3 NA
21	Leisure Participation - play cards / games	1	2 3 NA
22	Leisure - operate tape/CD player / radio / TV	1	2 3 NA
Comments:			
READING			
23	Reading - telephone directory	1	2 3 NA
24	Reading - TV guide	1	2 3 NA
25	Reading - books / Bible (standard print size)	1	2 3 NA
26	Reading - newspapers	1	2 3 NA
27	Reading - magazines / periodicals (standard print size)	1	2 3 NA
28	Reading - labels / instructions	1	2 3 NA
29	Reading - newspaper advertisements	1	2 3 NA
30	Read Timepiece - read watch	1	2 3 NA
31	Reading Timepiece - read clock	1	2 3 NA
Comments:			

<b>Writing</b>				
32	Writing - legible personal list that can be read back	1	2	3 NA
33	Writing - legibly address envelope	1	2	3 NA
34	Writing - legible signature	1	2	3 NA
Comments:				
<b>MOBILITY</b>				
35	Community/Social Participation - dine in a restaurant	1	2	3 NA
36	Functional Mobility - ascend / descend stairs	1	2	3 NA
37	Functional Mobility - adjust to changes in walking surface	1	2	3 NA
38	Functional Mobility - avoid collisions / tripping	1	2	3 NA
Comments:				

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Dr. Mary Warren from the University of Alabama at Birmingham granted permission to use the SRAFP for this study (personal communication, June 7, 2012).

## Task Descriptions

1. *Telephone directory*: reads well enough to gain desired information
2. *TV guide*: reads well enough to gain desired information
3. *Books/Bible*: standard print format; reads well enough to obtain enjoyment from activity
4. *Newspapers*: standard print format; reads well enough to obtain enjoyment from activity
5. *Magazines/periodical*: standard print format; reads well enough to obtain enjoyment from activity
6. *Mending*: threads needle; accurately cuts with scissors and attaches a button or repairs a tear
7. *Read recipes*: read recipes and/or package instructions accurately; within a reasonable amount of time
8. *Other leisure activities important to the client*. Rate ability to complete activity with sufficient speed, accuracy and effort so that the activity is enjoyable and rewarding
9. *Read labels/ instructions*: reads well enough to gain desired information
10. *Read newspaper advertisements*: reads well enough to gain desired information
11. *Manage financial records*: maintains organized system for bills/financial statements permitting quick document retrieval; makes legible entries into financial records
12. *Read bills/financial statements*: locates and accurately identify company, amount due, and qualifying statements within time period that the client feels is reasonable
13. *Write check or money order*: completes all areas of the check/money order legibly enough for another person to read the check/order; makes accurate, legible, written entry into check ledger; able to complete task within a reasonable amount of time in community environments
14. *Play cards/games*: plays with others or by self with sufficient speed, accuracy and/or effort that the game is enjoyable as a leisure pursuit
15. *Shopping*: locates and selects desired item for self (either by visually identifying item or seeking appropriate assistance); accurately pays for item without assistance; *count coins, bills, make change*: identifies, organize and exchange money accurately within a reasonable amount of time in community environments
16. *Personal list*: list or short note that writer can read back days later; another person can read list
17. *Dine in a restaurant*: selects foods (by reading menu or seeking appropriate assistance); locates table items and foods and eat food selection with acceptable level of neatness
18. *Address envelope*: positions address accurately; able to stay on line; writing is legible to unfamiliar reader

19. *Use of oven*: sets temperature accurately; tells when oven is on/off; monitors food accurately when baking; transfers food into and out of oven safely and without spillage
20. *Own signature*: positions signature accurately and stays on line; signature is legible to unfamiliar reader; able to complete task both at home and in community as needed
21. *Retrieve telephone #*: accurately uses address book, phone memory function or own memory to recall familiar #; telephone directory or directory assistance for unfamiliar #
22. *Chop/slice/peel*: handles knives and peelers safely; cuts foods into relatively uniform and appropriately size pieces; peels vegetable completely with minimal amount of waste
23. *Read watch*: can accurately read at least one portable timepiece in community environments as well as at home
24. *Laundering*: accurately sets washing machine/dryer dials; measures dry and liquid cleaners; treat stains
25. *Read clock*: has at least one clock that can accurately read both during the day and at night
26. *Pour/measure liquids/dry goods*: identify correct measuring utensil; fill cup or spoon accurately with minimal spillage
27. *Use of burners*: sets desired temperature accurately; tells when burners are on/off; accurately and safely places pans onto burner; transfers food safely and without spillage
28. *Ascend/descend stairs*: safely navigates stairs (with safety features rails, good lighting etc.) in familiar environments
29. *Use microwave*: locates and select all settings accurately; transfer food in/out safely and without spillage
30. *Physical operation of telephone*: accurately dials/push telephone numbers - sequencing numbers or using speed dial
31. *Adjust to changes in walking surfaces*: negotiates curbs, ramps, and transitions between surfaces (between carpet and vinyl or broken areas on sidewalks etc) without stopping, long hesitations, probing with cane or assistance.
32. *Medication routine*: identifies medications and takes accurate dosages; accurately performs health - monitoring tasks (glucose monitor, blood pressure, weight)
33. *Operate tape/CD player/radio/TV*; accurately locates and selects desired settings on devices
34. *Grooming*: accurately shaves; cleans/maintain shaver/razor; combs, brush, styles washes hair; applies toothpaste, denture cream; safely clean, trim/ file fingernails and toenails
35. *Eating*: locates items at place setting & food on plate; seasons food to desired taste; evenly spreads toppings onto foods; cuts meat; eats "messy" foods with minimal spillage

- 36. *Locate/organize items in kitchen*; locates desired items accurately and safely; stores items in a manner that promotes safety and efficient relocation
- 37. *Dressing*: able to locate needed items of clothing; identifies clothing colors; matches outfits appropriately
- 38. *Avoid collisions/ tripping*: safely ambulates around objects and obstacles in familiar environments

**APPENDIX C THE OCCUPATIONAL LIVES OF INDIVIDUALS WITH VISUAL  
IMPAIRMENT DEMOGRAPHIC QUESTIONNAIRE (OLIVIDQ)**

## The Occupational Lives of Individuals with Visual Impairment Demographic Questionnaire (OLIVIDQ)

**Name:** \_\_\_\_\_

**Demographic Questions:**

1. Age: \_\_\_\_\_
2. Gender: Male \_\_\_\_\_ Female \_\_\_\_\_ Other \_\_\_\_\_
3. Race: White \_\_\_\_\_ Black or African American \_\_\_\_\_  
Asian \_\_\_\_\_ American Indian or Alaska Native \_\_\_\_\_  
Some other race \_\_\_\_\_ Two or more races \_\_\_\_\_
4. Ethnicity: Hispanic or Latino \_\_\_\_\_ Not Hispanic or Latino \_\_\_\_\_
5. Do you engage in some type of productive activity like work or volunteering? If so, describe the activity.  
Work: \_\_\_\_\_  
Volunteer: \_\_\_\_\_
6. What county do you live in? \_\_\_\_\_
7. Living Arrangement: Alone? \_\_\_\_\_  
With Someone (specify): \_\_\_\_\_
8. Do you live in an apartment, condo, house, or different setting? \_\_\_\_\_
9. Do you have steps to enter your home or within your home? \_\_\_\_\_
10. Do you care for others? \_\_\_\_\_
11. Do you care for pets? \_\_\_\_\_
12. Do you have access to transportation? \_\_\_\_\_ If so, what type? \_\_\_\_\_
13. Do you participate in activities at the Lackawanna Blind Association? \_\_\_\_\_  
If so, what activities and for how long? \_\_\_\_\_  
\_\_\_\_\_
14. How long have you had problems with your vision? \_\_\_\_\_
15. What diagnosis were you given? \_\_\_\_\_



**Name:** \_\_\_\_\_

16. Did you receive any type of optical device, such as eyeglasses or a magnifier, to help you with your vision? \_\_\_\_\_  
If so, what type? \_\_\_\_\_  
\_\_\_\_\_
17. Did you receive any type of rehabilitation or training to assist you with your vision problems, and if so, which services and for how long? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
18. How would you describe your overall health and quality of life?  
Excellent \_\_\_\_\_, Good \_\_\_\_\_, Fair \_\_\_\_\_, Poor \_\_\_\_\_
19. How would you rate your emotional well-being on a scale of one to ten, where ten is very happy and one is very sad? \_\_\_\_\_
20. How would you rate your life satisfaction on a scale of one to ten, where ten is very satisfied and one is not satisfied? \_\_\_\_\_

**Visual Assessments:**

1. Eye dominance: left or right (circle dominant eye)
2. Visual Acuity:
  - a. Intermediate:
    - i. OU: 20/\_\_\_\_\_
3. Contrast Sensitivity Function: \_\_\_\_\_
4. What do you see?

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**APPENDIX D THE NASTASI OCCUPATIONAL LIVES OF INDIVIDUALS WITH  
VISUAL IMPAIRMENT PROFILE (NOLIVIP)**

**The Nastasi Occupational Lives of Individuals with Visual Impairment  
Profile (NOLIVIP)**

1. Tell me how you see. Describe what you see in this room.
  - How do you perceive your vision? Do you use vision? Do you use other strategies?
2. Have there been changes in your vision over time?
  - How have these changes affected your life?
3. Tell me about a typical day in your life now.
  - What activities do you participate in? Describe to me your participation in the activities that are most meaningful to you. What does participating in these activities mean to you?
  - Do you leave your home? Describe the activities that you participate in outside of your home. Tell me about your travel, how do you manage travel in the community (car, buses, walking, etc.)?
4. Tell me about a typical week in your life now.
  - What activities do you participate in? Describe to me your participation in the activities that are most meaningful to you. What does participating in these activities mean to you?
  - Do you leave your home? Describe the activities that you participate in outside of your home. Tell me about your travel, how do you manage travel in the community (car, buses, walking, etc.)?
5. Tell me about a typical month in your life now.
  - What activities do you participate in? Describe to me your participation in the activities that are most meaningful to you. What does participating in these activities mean to you?
  - Do you leave your home? Describe the activities that you participate in outside of your home. Tell me about your travel, how do you manage travel in the community (car, buses, walking, etc.)?
6. Tell me about your seasonal routines in your life now. (spring, summer, fall, and winter)
  - What activities do you participate in? Describe to me your participation in the activities that are most meaningful to you. What does participating in these activities mean to you?

- Do you leave your home? Describe the activities that you participate in outside of your home. Tell me about your travel, how do you manage travel in the community (car, buses, walking, etc.)?
7. Tell me about a time or situation when you were able to successfully complete an activity.
    - What was the environment like? What was the lighting like? What were the noise levels? Did you use any adaptive equipment (such as large print items, bold pens, etc)? Were there other people around?
  8. Tell me about a time or situation when your vision has prevented you from successfully completing an activity.
    - What was the environment like? What was the lighting like? What were the noise levels? Did you use any adaptive equipment (such as large print items, bold pens, etc)? Were there other people around?
  9. When you encounter a problem, how do you go about solving the problem?
    - Do you take charge? Do you take a passive approach? Do you avoid the problem? Tell me about a time where you had to solve a problem. How did you go about solving the problem?
  10. Describe the strategies that you use to participate in leisure, work, or social activities.
  11. Is there any other information related to your vision that you would like to share?

**APPENDIX E FOLLOW-UP QUESTIONS SESSIONS I-III**

### **Follow-up Questions Sessions I-III**

1. Think about yourself before and after you had your vision problems.
  - Tell me in your own words who you are now.
  - Tell me how your vision has affected who you are.
2. Tell me about your life.
  - What makes your life unique to you?
3. During your interview, you mentioned belonging to different organizations and clubs. Tell me more about your participation in the different clubs and organizations.
4. During your interview, you mentioned that there are things that you no longer do or that you no longer plan to do.
  - Tell me more about this.
5. Tell me about your hard places or challenges that you have in your life with your low vision.
  - Tell me more about them.
6. During your interview, you mentioned many strategies that you use on a daily basis. Tell me how you cope with your vision loss.
  - Tell me more about your coping strategies.
  - Tell me about your greatest challenge in coping and living with low vision.
7. Tell me more about your participation in the class that I observed you in at the Lackawanna Blind Association.
  - Tell me about why you keep coming to the class.
8. Is there anything else that you would like to share with me?

## **APPENDIX F THE FINAL INTERVIEW**

### Final Interview

1. The theme of gratitude and/or thankfulness emerged from the interviews. There was thankfulness for the remaining vision as well as the ability to participate and complete activities.  
- Does this theme apply to you?
2. The theme of motivation and strive for independence emerged from the interviews. If you wanted to do something then you would find a way to do it.  
- Does this theme apply to you?
3. The theme of family/friend support emerged from the interviews. Family and/or friends were available to help you.  
- Does this theme apply to you?
4. The theme of strategies emerged from the interviews. Strategies included organization, memory, use of magnification and/or large print.  
- Does this theme apply to you?
5. The theme of participation emerged from the interviews. When possible you would participate in activities and/or clubs outside of the home.  
- Does this theme apply to you?
6. The theme of loss of participation emerged from the interviews. Due to your vision, you have given up or changed activities that you have completed in the past.  
- Does this theme apply to you?

Visual Acuity Intermediate: \_\_\_\_\_

Birth date: \_\_\_\_\_

7. Is there any other information that you would like to share with me?
8. Is there anything that you would like to address that was not covered during the interviews or the findings?



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Zemke, R., & Clark, F. (1996). *Occupational Science the Evolving Discipline*.  
Philadelphia, PA: F. A. Davis.

## CURRICULUM VITAE

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DEGREE AND DATE TO BE CONFERRED: ScD, 2014

### COLLEGIATE INSTITUTIONS ATTENDED:

Towson University, 2011-2014, ScD, 2014

Major: Occupational Science

Boston University, 2009-2010, OTD, 2010

Major: Occupational Therapy

University of Alabama at Birmingham, 2005-2007, Graduate Certificate, 2007

Major: Low Vision Rehabilitation

Tufts University, 2001-2002, MA, 2002

Major: Occupational Therapy

University of Scranton, 1996-2001, BS, 2001

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### PROFESSIONAL PUBLICATIONS:

Nastasi, J. (2014). Chapter 6 – Meaning and dynamic of occupation and activity. In K. Jacobs, N. MacRae, & K. Sladyk (Editors), *Occupational Therapy Essentials for Clinical Competence, Second Edition*. Slack Incorporated.

Nastasi, J. (2014). Chapter 43 – Fieldwork education. In K. Jacobs, N. MacRae, & K. Sladyk (Editors), *Occupational Therapy Essentials for Clinical Competence, Second Edition*. Slack Incorporated.

Nastasi, J., Bello, A., Bender, E., Davitt, K., Mahon, K., Marandino, A., Menendez, N., Munoz, M., Tripodi, C., & Zubia, S. (2013). *Living with low vision tip sheet*. Bethesda, MARYLAND: American Occupational Therapy Association.

Stav, W., & Nastasi, J. (2013). Critically appraised topic on evidence-based literature review question: What is the evidence for the effect of policy and

community mobility programs (e.g., alternative transportation, walkable communities, education, driving cessation programs) on the performance and participation of older adults. Retrieved from  
<http://www.aota.org/ccl/od/community-mobility.aspx>

Nastasi, J. (2013). Fieldwork. *Work*, 43(3), 245.

Nastasi, J. (2013). Specialty level II fieldwork in low vision rehabilitation. *Work*, 43(3), 361-378.

Nastasi, J. A. (2012). Occupational Therapy Consultant. In M. Cameron (Editor), *Physical agents in rehabilitation from research to practice* (4<sup>th</sup> ed.). Elsevier.

Nastasi, J. A. (2012, June). Specialty level II fieldwork in low vision rehabilitation. *OT Practice*, 17(11), 13-16.

Nastasi, J., Krieger, S., & Rucker, J. (2012). Chapter 11 – Rehabilitation for visual impairments. In M. Finlayson (Editor), *Multiple sclerosis rehabilitation: From impairment to participation*. CRC Press/Taylor Francis.

#### PROFESSIONAL POSITIONS HELD:

Commissioner, Commission on Education – POTA, 2012 – 2016, [www.pota.org](http://www.pota.org)

Low Vision Coordinator for the Productive Aging SIS – NYSOTA, 2011 – 2013,  
 NYSOTA, PO Box 609, Glenmont, NY 12077

Program Committee Co-Chair 2011 State Conference – NYSOTA, 2010 – 2011,  
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Co-monitor Low Vision Listserv/Forum Advisory Council – AOTA, 2010 –  
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Secretary for Hudson Taconic District of NYSOTA, 2009 – 2010, NYSOTA, PO  
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Low Vision Listserv/Forum Advisory Council – AOTA, 2009 – 2010, AOTA, 4720  
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Membership Chair – Executive Board – NYSOTA, 2004 – 2011, NYSOTA, PO  
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Dutchess/Putnam Representative for Hudson Taconic District of NYSOTA, 2003  
 – 2009, NYSOTA, PO Box 609, Glenmont, NY 12077

Strategic Planning Committee – NYSOTA, 2003, NYSOTA, PO Box 609,  
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Continuing Education Committee for AOTA Providership – NYSOTA, 2003,  
NYSOTA, PO Box 609, Glenmont, NY 12077  
Program Committee Co-Chair 2003 State Conference – NYSOTA, 2002 – 2003,  
NYSOTA, PO Box 609, Glenmont, NY 12077

**AWARDS:**

Roster of Fellows, AOTA, 2014  
Specialty Certification in Low Vision, AOTA, 2009-2019  
Delta Gamma Fellow for AFB's 2009 Josephine L. Taylor Leadership Institute

**PROFESSIONAL ASSOCIATIONS:**

Envision University Oculus Society, 2013 - Present  
Pennsylvania Occupational Therapy Association, 2011 - Present  
New York State Occupational Therapy Association, 2002 - Present  
World Federation of Occupational Therapists, 1999 - Present  
American Occupational Therapy Association, 1996 - Present



